

# Family caregivers' perceived symptom distress of persons with a primary malignant brain tumor

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Boston College

William F. Connell School of Nursing

FAMILY CAREGIVERS' PERCEIVED SYMPTOM DISTRESS OF PERSONS  
WITH A PRIMARY MALIGNANT BRAIN TUMOR

A dissertation

by

NADINE M. LINENDOLL

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for the degree of

Doctor of Philosophy

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## ABSTRACT

FAMILY CAREGIVERS' PERCEIVED SYMPTOM DISTRESS OF PERSONS  
WITH A PRIMARY MALIGNANT BRAIN TUMOR

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The diagnosis of a primary malignant brain tumor (PMBT) can be devastating for individuals and their families due to the limited treatment options and poor prognosis. Patients often rely on family members to manage their care; however, many caregivers feel under-prepared and overwhelmed by the experience. Though caring for a person with a PMBT is challenging and complex, little research has addressed the family caregiver's performance. The purpose of this study was to identify the extent to which preparedness and caregiver role strain explained the family caregiver's performance in symptom management.

An adapted theoretical framework, The Theory of Unpleasant Symptoms for Family Caregivers, guided this study. The study employed a descriptive, correlational research design in which the researcher obtained cross-sectional data during one collection period. The participants were adults who identified themselves as family caregivers of persons with a PMBT. Forty caregivers were enrolled in the study at the Brain Tumor Center at Beth Israel Deaconess Medical Center.

Results from the regression analyses indicated that caregiver role strain and preparedness explained 31% of the variance (adjusted  $R^2$ ) in perceived psychological symptom distress and 29% (adjusted  $R^2$ ) of the variance in perceived physical symptom

distress. Caregiver role strain was the major contributor to psychological ( $B=.68$ ,  $p=.000$ ) and physical symptoms ( $B=.48$ ,  $p=0.001$ ), indicating that higher levels of caregiver role strain were predictive of higher levels of perceived symptom distress and this relationship was strong. Preparedness contributed less to the explained variance in psychological ( $B=-.24$ ,  $p=.20$ ) and physical symptoms ( $B=-.21$ ,  $p=.14$ ). The negative beta indicates that higher preparedness was related to lower perceived symptom distress, but this relationship was small when compared with role strain.

This study informs clinicians in neuro-oncology that care giver role strain is often high in family caregivers of patients with a PMBT and can have a negative impact on caregiver performance. These findings also support the need for more tailored nursing interventions to assist caregivers with ways to decrease caregiver role strain and improve caregiver preparedness.

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I would also like to thank the Boston College Connell School of Nursing faculty for their wisdom and dedication to nursing. I came to Boston College with very little research experience, and have grown tremendously through the influence of my teachers. I would especially like to thank Sister Callista Roy, Ph.D., whom I worked with as a research fellow. It was an honor to work so closely with a living legend.

Finally, I would like to thank my parents, three sisters and new husband for their understanding and support. Since I have been so blessed throughout this process, my hope is to give back to others. My challenge, as a nurse researcher, from this project forward is to improve the daily life of individuals struggling with terminal illness.

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## CHAPTER 1

### Introduction

The diagnosis of a primary malignant brain tumor (PMBT) can be devastating for individuals and their families due to the limited treatment options and poor prognosis. Most patients can expect rapid debilitation and a median survival time of only one to five years (National Cancer Institute, 2007). Though neuro-oncology research continues with new innovations in chemotherapy and genetic testing, these new treatments have not significantly improved patients' longevity (Wong & Linendoll, 2007). Since the 1980s most patients undergo a standard treatment regimen including a combination of surgery, chemotherapy and radiation (Chang, Parney, Huang, Anderson, Asher, Bernstein, et al. 2005). Throughout treatment, these patients often suffer from complex physical and psychological symptoms that are distressing.

As patients become debilitated they often rely on family members to manage their care; however, many caregivers have no formal training and feel under-prepared for and overwhelmed by the caregiving experience (Ferrell et al., 1991; Hudson, Aranda & McMurray, 2002; Tilden, Tolle, Drach & Perrin, 2004). Their lack of preparedness and stress often leads to more stress, anxiety, frustration and other negative outcomes. Gallagher-Thompson and Coon (2007) and Schulz et al. (2007) have thoroughly reviewed caregiver distress and suffering in their work and provide a compelling picture of the potential burden that caregivers face. Though it is clear that caring for persons with a PMBT is challenging and complex, little research has been done to address the family caregivers' performance, especially in symptom management. The purpose of this

study was to identify the extent to which preparedness in caregiving and caregiver role strain explained the family caregivers' performance in symptom management. In this study, performance was measured by the caregivers' perceived symptom distress of their family member with a PMBT. Information from this study will be used to develop nursing interventions aimed to improve the performance of family caregivers. Results will also help to develop nursing knowledge applicable to this population of caregivers.

Epidemiological studies show a steady increase in the incidence of PMBTs (Sundee, Lynch, Sibenaller & Ryken, 2006). The National Cancer Institute (NCI) estimates that, in 2007, 20,500 adults and children (11,170 males and 9,330 females) will be diagnosed with cancer of the brain and other nervous system malignancies. The NCI also estimates that, in 2007, 12,740 individuals diagnosed during that year or in prior years will die (National Cancer Institute, 2007). While their survival time is very limited, the Central Brain Tumor Registry of the United States estimates that 81,000 individuals currently live with a PMBT in the United States (CBTRUS, 2006). These patients rely heavily on their caregivers, who are in need of more supportive interventions from their nurses and other healthcare providers.

Although malignant brain tumors affect thousands of individuals each year, treatments that have improved longevity have not significantly advanced for some time (Wong & Linendoll, 2007). For the last three decades, the standard of care has included palliative surgery, radiation and chemotherapy (Chang et al., 2005). Since many of these treatment modalities cause toxic side effects, persons with a PMBT often experience symptoms from both their tumor and their treatment regimens, including both oncologic

and neurologic symptoms (Lovely, 2004). As a result, many PMBT patients suffer a very progressive decline and require daily assistance from family caregivers.

Due to an increased availability of community services, many family caregivers are able to provide care in their homes, which can significantly increase their responsibilities (National Family Caregiver Association, 2000). Patients often prefer home-based care over hospitals or nursing homes because such care includes feelings of familiarity, comfort and the presence of loved ones (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004; Higginson & Sen-Gupta, 2000). Singer, Bachner, Shvartzman, and Carmel (2005) found that family caregivers also prefer home-based care even though such care often entails complex problems and challenges.

Research has shown that functioning as a family caregiver is a risky endeavor. Family caregivers are at risk for a multitude of physical, psychological and social problems. These can include higher rates of mortality (Schulz & Beach, 1999), decreased wound healing (Kiecolt-Glaser, Marucha, Malarkey, Mercado & Glaser, 1995), depression (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001; Sherwood, Given, Given & Von Eye, 2005), economic burden (Emanuel, Fairclough, Slutsman, & Emanuel, 2000), emotional exhaustion (Tilden et al., 2004) and drastic changes in social lifestyle (Covinsky et al., 1994; Emanuel, Fairclough, Slutsman, & Emanuel, 2000). However, Eldridge (2004) found that even though caregiving can be an arduous and exhausting process, most caregivers are task-centered and strive to do everything that they can for their family member. In addition, they do not limit their care to medical

interventions, but also want to be present, hold, talk to and provide comfort to their loved ones (Pierce, 1999).

Unfortunately, although family caregivers often want to help, research indicates that healthcare professionals not only rarely rely on them as resources (Persson, Rasmussen, & Hallberg, 1998), but also provide them with inadequate support (Visser et al., 2004). This is especially true with symptom management. Ferrell et al. (1991) found that caregivers often observe negative symptoms in their family member, but are unsure how to treat them. Because they receive insufficient preparation in responding to symptoms, caregivers often learn to care for their family member through trial and error. This inadequate preparation can lead to frustration for both the caregiver and the care recipient. Berkman (1995) suggests that, because patients are part of a larger network of family and friends, nurses and other healthcare workers should focus on promoting social, family and community support. By aiding the family caregiver, the nurse has the opportunity to enhance the caregiving experience and promote caregiver efficacy and optimism.

### Significance

Caring for persons with a PMBT is complex because they will likely suffer a rapid decline with complex symptoms. Although research clearly indicates that family caregiving is challenging and often burdensome, the incidence of family caregiving continues to increase. Though research has shown that family caregivers often function with inadequate support and preparedness (Ferrell et al., 1991; Hudson et al., 2002; Tilden et al., 2004) little research has been done to address how these perceptions affect

the family caregivers' performance, especially regarding symptom management. The purpose of this study was to identify the extent to which caregiver role strain and preparedness explain the family caregivers' performance, as measured by the perceived symptom distress of persons with a PMBT. Information from this study will be used to develop future theory-guided nursing interventions to improve the performance of family caregivers.

### Research Questions

Specifically, the following theory-based research questions were answered:

- 1.) To what extent do caregiver role strain and preparedness explain family caregivers' perceived psychological symptom distress of persons with a PMBT? 2.) To what extent do caregiver role strain and preparedness explain family caregivers' perceived physical symptom distress of persons with a PMBT?

### Hypotheses

1. Family caregivers who rate themselves with higher levels of caregiver role strain and lower levels of preparedness will have increased levels of perceived psychological symptom distress when caring for persons with a PMBT.
2. Family caregivers who rate themselves with higher levels of caregiver role strain and lower levels of preparedness will have increased levels of perceived physical symptom distress when caring for persons with a PMBT.

### Operational Definitions

The following terms are defined for the purpose of this study:



### *Independent Variables*

*Caregiver role strain.* The North American Nursing Diagnosis Association (NANDA) accepted the term “caregiver role strain” in 1992 as a family-oriented nursing diagnosis, which occurs when a caregiver feels difficulty performing aspects of the family caregiver role (Burns, Archbold, Stewart & Shelton, 1993). Role strain refers to the multidimensional aspects of caregiver burden (Archbold, Stewart, Greenlick, & Harvath, 1990). Caregiver role strain was measured in this study by respondent scores on three sub-scales of caregiver role strain from the Family Caregiving Inventory including tension, worry and global strain (Archobold & Stewart, 1986).

*Family caregiver preparedness.* In viewing caregiving as a role, “preparedness” indicates how well informed and comfortable a caregiver is with all aspects of his or her role (Archbold et al., 1990). Preparedness refers to the caregiver’s assessment of his or her own readiness to provide care rather than the adequacy of providing care (Schumacher, Stewart & Archbold, 1998). Each caregiver's preparedness was measured by his or her scores on the preparedness subscale of the Family Caregiving Inventory (Archbold & Stewart, 1986).

### *Descriptive Variables*

*Family caregiver.* The family caregiver self-identified as a care taker and consistently tended to the physical and emotional well-being of the person with a PMBT. The family caregiver had a biological or emotionally close relationship with the patient; however, the family caregiver could not identify as a paid caregiver.

*Primary malignant brain tumor.* This study included caregivers of patients with a primary malignant brain tumor (PMBT) of glial tissue because such patients often experience a more intense and rapid disease trajectory compared to patients with benign tumors of other origin. Patients with a PMBT also differ from patients with secondary malignant tumors in their symptom presentation and treatment regimens. The 2000 World Health Organization (WHO) classification of tumors is widely used in clinical practice. The traditional WHO system divides brain tumors into seven major categories including: tumors arising from neuroepithelial tissue, from meninges, peripheral nerves, lymphomas and hematologic neoplasms; germ cell tumors, sellar tumors, and metastatic tumors (Kleihues, 2000). This study only included patients with malignant glial tumors, which arise from the neuroepithelial tissue of the brain. Glial tumors include astrocytomas, glioblastomas, oligodendrogliomas, ependymomas, mixed gliomas and other malignant gliomas (See Appendix A).

#### *Dependent Variable*

*Perceived symptom distress.* In this study, performance was measured by the caregiver's perceived symptom distress of their family member with a PMBT. Perceived symptom distress describes the caregivers' perception of the psychological and physiological symptoms that their family members experience. The concept, "perceived symptom distress," is part of a growing corpus of literature, which has identified a dyadic relationship that occurs between caregiver and care receiver, whereby they are influenced by one another's positive and negative outcomes (Fleming et al., 2006; Lobchuk, 2003; Mystakidou, Tsilika, Parpa, Galanos & Vlahos, 2007; Schulz et al., 2007). Perceived

symptom distress was measured in this study by respondent scores on the Memorial Symptom Assessment Scale (MSAS), which included both physical and psychological symptoms (Portenoy et al., 1994). The MSAS was adapted in this study to include four symptoms, common in the patients with PMBT, which were not included in the original version.

#### Assumptions

This study assumes that taking care of a person with a PMBT is a challenging and complicated task. This is due to the patient's rapid decline and complex symptoms. Thus, it is assumed that family caregivers of persons with a PMBT will experience caregiver role strain and its related unpleasant symptoms.

#### Limitations

This study was limited by three major factors. First, since not all participants who were eligible for the study participated, non-participants may have differed from participants. Second, this study was limited to English speaking family caregivers and may not be generalizable to non-English speaking family caregivers. Third, this study was limited to caregivers of patients with a PMBT and may not be generalizable to patients with other disease processes.

## CHAPTER 2

### Literature Review

This chapter introduces the theoretical framework, adapted from the Theory of Unpleasant Symptoms (TOUS), which was the underpinning of the study. It also discusses the work of Archbold et al., (1990) who studied family caregivers and developed the concepts of caregiver role strain and preparedness, which were used in the adapted theoretic model. Lastly, this chapter provides a synthesis of the current literature relevant to family caregiving of patients with a PMBT. Because an extensive body of caregiving literature exists that is far too large for review in this chapter, only information that was most pertinent to the PMBT population, including work in oncology, neuro-oncology and palliative care, was included.

### Theoretical Framework

In this study, an adapted theoretical framework was created to best guide the research questions. The framework is comprised of key concepts from the Theory of Unpleasant Symptoms (TOUS) (Lenz, Pugh, Milligan, Gift, & Suppe, 1997) and the work of Archbold and colleges (Archbold et al., 1990; Schumacher, Stewart & Archbold, 2007). The following section explains how and why this model was created.

Previous research has identified the presence of caregiver role strain and the lack of preparedness in family caregivers; however, a gap in knowledge still exists regarding how role strain and preparedness affect caregiver performance, especially in symptom management. The goal of this study was not to repeat descriptive work on caregiver role strain and the lack preparedness, but to explore how these variables affected performance.

This is an important question since caregivers have identified performance, or ability to provide good care, as their highest goal (Andershed & Ternestedt, 1999; Persson et al., 1998; Pierce, 1999).

The TOUS was an applicable framework for this study because it is concerned with how influencing factors affect performance. Historically, the TOUS was developed as a middle range nursing theory, which grew out of clinical practice when several nurse researchers recognized that a patient's symptoms were highly complex and individualized (Lenz et. al., 1997). In the TOUS, physiologic, psychological, and situational factors influence the occurrence of symptoms. The influencing factors intermix and can have a compounding effect on one another. If one or more of the factors become negative, then the patient can suffer from unpleasant symptoms and decreased performance.

A shortcoming of the TOUS for this study is that it was originally developed to explore the symptoms and performance of the patient and not the family caregiver. In order to adapt the TOUS to research with the family caregiver, it was decided to add concepts from Archbold and colleagues (1990), who have done extensive empirical and theoretical work with family caregiving. Specifically, Archbold et al.'s (1990) concepts of "caregiver role strain" and "preparedness" were added to define the psychological and situational influencing factors on the family caregiver's performance. Thus, the final adapted theoretical framework used in this study became a hybrid of the TOUS concepts of influencing factors and performance, and Archbold and colleagues' (1990) concepts of family caregiver preparedness and caregiver role strain. The combination of these two

theories was the best lens through which to explore performance within the context of family caregiving (See Figure 1).

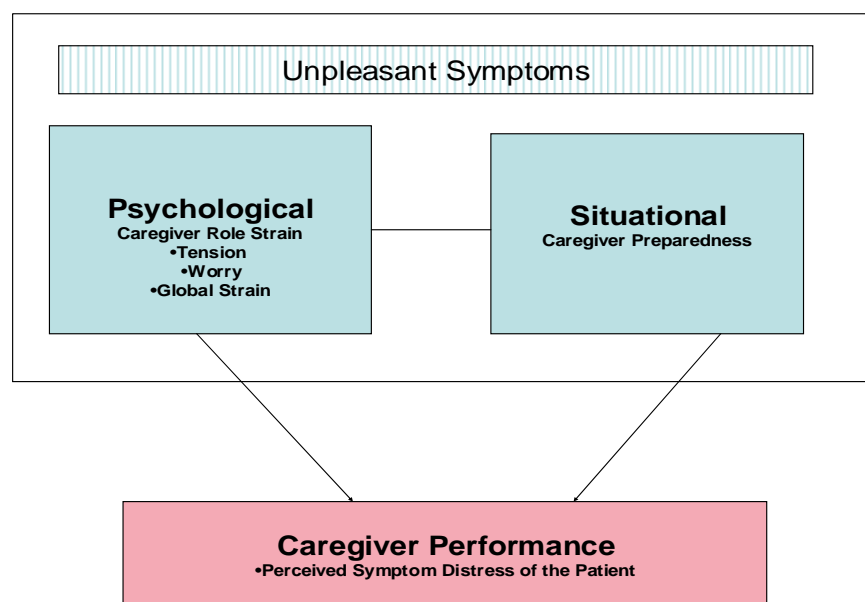


Figure 1. The Theory of Unpleasant Symptoms Adapted for Family Caregivers of Persons with a PMBT.

*The Theory of Unpleasant Symptoms.*

The following section contains three parts. The first part gives a description of the original development of the TOUS. The second part details how the TOUS has been used in previous research studies. The last part describes an important modification of the TOUS in this study, which combined the concepts of influencing factors and

unpleasant symptoms, since they occur simultaneously and iteratively in the family caregiver.

The TOUS is a middle range nursing theory, which grew out of clinical practice when several nurse researchers recognized that a patient with chronic obstructive pulmonary disease (COPD) had highly complex symptoms (Lenz et al., 1997). In their model, Lenz and colleagues (1997) define five major components of the TOUS. First, physiological factors refer to the normal or abnormal functions of the body such as age or co-morbidities. Second, psychological factors include the mental state or mood of the individual, how he or she responds to the illness, and how he or she finds meaning within the experience. Third, situational factors refer to both the overall physical environment of the patient, such as the level of heat and noise, and the social aspects of the patient, such as his or her financial status, marital status, social status and knowledge of the disease process. Fourth, unpleasant symptoms refer to the perceived indicators of change in normal mental and bodily function that have the subjective feeling of a threat to health. Unpleasant systems are rated according to their degree of occurrence, intensity, timing, distress level and quality. And, lastly, performance describes the outcome of the symptom experience, including the patient's cognitive and functional activities, such as his or her social interaction and participation in activities of daily living.

In the TOUS, symptoms do not occur in isolation of one another. Instead, the symptoms have multidimensional aspects, occur simultaneously, and can catalyze one another. Symptoms are highly variable because they are influenced by the physiologic, psychological and situational factors of the individual. If one or more of the influencing

factors become negative, then the patient can suffer from unpleasant symptoms and decreased performance.

The TOUS has been used as the theoretical framework in several studies (Corwin, Brownstead, Barton, Heckard & Morin, 2005; Liu, 2006; McCann & Boore, 2000; Reishtein, 2005). Pugh and Milligan (1998) used the TOUS to help inform an educational intervention in which they aimed to improve new mothers' success and longevity in breast-feeding. Their work is the most relevant to this study because they apply the TOUS to mothers, who provide care to their newborns. In their study, the researchers made two home visits at three or four days, and then twelve days post-partum. These visits addressed all three of the influencing factors of the TOUS including information on health promotion (physical), social support (psychological), and environmental factors (situational) to improve breast-feeding. Unlike other interventions that seek to alleviate just one unpleasant symptom of painful breast-feeding, this study used the TOUS holistic approach to address multiple aspects that would contribute to the mother's breast-feeding experience, including the mental, physical and situational factors. This intervention proved to be successful with new mothers and had two positive outcomes: lower fatigue and continued breast feeding six weeks longer than the control group. This study supports the assertion that the TOUS framework is relevant to research with caregivers.

The current study modified the TOUS by combining the concepts of influencing factors and unpleasant symptoms, in order to reflect the clinically observed experience of family caregivers. In the original TOUS, the physical, psychological and situational



factors cause unpleasant symptoms, which ultimately lead to decreased performance. For family caregivers of persons with a PMBT, influencing factors can not be separated from their unpleasant symptoms. In other words, the situational and psychological factors of caregiver role strain and preparedness do not cause unpleasant symptoms, but instead they are the unpleasant symptoms themselves. For example, when a caregiver has high levels of worry, the worry simultaneously is both an influencing factor and an unpleasant symptom - both of which affect performance. A second example is when the caregiver is very tense. The tension is an influencing factor and also an unpleasant symptom, which again affects performance. Thus, in this study the psychological factors (worry, tension and global strain) and the situational factor (preparedness) simultaneously are both the influencing factors and the unpleasant symptoms of the caregiver that ultimately were hypothesized to affect their performance.

#### *Family Caregiver*

In the theoretical model developed for this study, the theoretical and empirical work of Archbold et al. (1990) was incorporated to add the perspective of the family caregiver. In their work, these researchers described caregiving as a role and were interested in how caregivers performed their role, and subsequently evaluated their efforts. As a result, Archbold and her colleagues developed the concepts of “preparedness” and “caregiver role strain” to further define the influencing factors on the caregivers’ performance. These two concepts are used in the adapted theoretical model of this study.

In the development of this model the psychological factor was operationalized as caregiver role strain. Caregiver role strain occurs as a multidimensional, family phenomenon whereby the family caregiver experiences difficulty when providing care (Burns et al., 1993). Archobold and colleagues (1990) studied nine aspects of role strain. Three of these aspects, including tension, worry and global strain, were incorporated into this adapted theoretical model. This was based on previous research in caregivers with persons with a PMBT, which suggests that caregiver role strain, in the forms of tension, strain and worry, are very high (Edvardsson & Ahlstrom, 2007; Keir et al., 2006; Sherwood et al., 2004).

In the model the situational factor was operationalized as caregiver preparedness. This variable describes how prepared an individual feels to take on the caregiving role. When developing this concept, Archobold and colleagues (1990) were influenced by previous work done on caregiver self-efficacy and caregiving mastery. Their concept of “preparedness” differed from previous work because it was domain-specific versus task-specific (Archbold, et al., 1990). In other words, Archbold et al. (1990) were concerned with the individuals’ ability to take on the overall role of the caregiver, rather than their ability to complete particular tasks or skills. In this study, the concept of preparedness was used to assess how prepared individuals feel to take on the role of a caregiver. To date, preparedness has been discussed more in general oncology and palliative care research and is not well defined within the PMBT population (Hudson, Aranda & Hayman-White, 2005; Schumacher, Stewart & Archbold, 2007).

### *The Final Adapted Theoretical Model*

The theoretical framework of this study provided a guide for investigating the factors that affect the family caregiver's performance when providing care to a person with a PMBT. The TOUS was an appropriate model for the family caregiver because, like Pugh and Milligan's (1998) study with new mothers, the family caregiver's ability to perform is influenced by complex and multidimensional factors. Archbold et al.'s (1990) work with family caregivers was also an appropriate addition to the theoretical framework because their research helps to define specific psychological and situational factors of the family caregiver including caregiver role strain and preparedness.

This study examined how the psychological factor of caregiver role strain and the situational factor of the lack of preparedness affect the performance of the family caregiver. In this study performance was conceptualized as the caregiver's perceived symptom distress of the patient. As the caregiver's performance declines, he or she has difficulty managing the symptoms of the patient, and thereby experiences a subsequent increase in the perceived symptom distress of the patient.

### *Review of the Family Caregiving Literature*

Caregiving is a complex activity that is influenced by the psychological, situational and physiological factors of the family caregiver. During caregiving these factors can catalyze and create positive and negative outcomes in the caregiver's performance. Understanding these complex interactions and their outcomes may help nurses prevent caregiver role strain, improve preparedness and maintain optimal performance of the family caregiver. The following section includes a review of the

literature that is most pertinent to the PMBT population, including work in oncology, neuro-oncology and palliative care.

*Psychological Factors of the Family Caregiver*

Negative psychological factors, such as stress, anxiety and worry, have been identified as common outcomes of caregiving, which can lead to decreased performance (Gallagher-Thompson & Coon, 2007). Although many caregivers experience psychological problems, research has found that healthcare providers rarely address their concerns (Osse, Vernooij-Dassen, Schade, & Grol, 2006). Psychological stressors are especially prevalent family caregivers of persons with PMBT, due to the rapid disease trajectory and limited treatment options. The following section presents the most current research of the psychological factors pertinent to this study, including caregivers' stress, tension and worry. It includes a description of the caregivers' stress response and the two most common themes of worry for caregivers - the rapid disease trajectory and the financial implications of the illness.

This section also includes a brief discussion of a positive psychological aspect of caregiving -- "the rewards of caregiving." Several studies have found that caregivers are able to identify positive rewards, such as increased meaning and joy during the caregiving experience (Hudson et al., 2005; Salmon, Kwak, Acquaviva, Brandt & Egan, 2005). Although the rewards of caregiving are not specifically addressed in this study, they are included in this review in order to provide a balanced perspective of both the positive and the negative psychological aspects of caregiving.

*Stress and tension.* Dumont et al. (2006) found high levels of stress in a population of family caregivers of oncology patients. They studied 212 family caregivers of patients with advanced cancer and found that 40-60% of the caregivers experienced a high level of psychological distress. The caregiver's level of distress increased as the patient's illness progressed and the patient lost his or her autonomy. In another study, Payne, Smith and Dean (1999) identified distress in a study of 45 caregivers of patients referred to community palliative care services. The researchers found that over 84% of the caregivers scored above the average threshold of psychological distress.

Keir et al. (2006) found high levels of stress in caregivers within the brain tumor population. The researchers did a cross-sectional study of 60 caregivers of patients with brain tumors and asked them to fill out a Perceived Stress Scale. This instrument is used to measure the degree to which life situations are perceived as stressful. The researchers found that 72% of the sample reported high levels of stress.

Sherwood et al. (2004) developed a conceptual model to help identify the causes of stress in caregivers of persons with a PMBT. Their framework differs from the one used in this study because, rather than focusing on caregiver performance, they ground their model in the work of Lazarus and Folkman and focus more on the caregiver's ability to cope (Folkman 1997; Lazarus 1966). Though conceptually different from the theoretical model used in this study, Sherwood et al.'s (2004) work is an important resource to help understand the "stress response" in family caregivers of persons with a PMBT.

In the Sherwood et al. (2004) model, caregivers respond physically and emotionally to the patient's symptoms and neurological status. Caregivers use internal resources, such as their own physical and emotional health, and external resources, such as family social support or home services, to provide care for their family members. Providing care elicits emotional and physical responses from caregivers, including caregiver stress. Their stress level constantly changes as the patient's condition progresses. The authors encourage healthcare providers to monitor the caregiver's stress level because PMBT patients often experience a very rapid disease trajectory, which can intensify stress and tension.

In several qualitative studies, family caregivers expressed existential and emotional distress with the feeling of being in a severe crisis (Persson et al., 1998; Rose, 1999). Pierce (1999) found that although a caregiver strives to be present with his or her family member, the overall experience can be extremely draining. Some caregivers reported feeling so overwhelmed and stressed during the caregiving experience that they could not think coherently. Later, many felt persistent regret and sadness over their state of mind and wished that they could have done things differently.

Swartz and Keir (2007) found that stressed caregivers are willing to participate in interventions to reduce tension. The researchers asked 60 caregivers of persons with brain tumors to choose which stress reducing interventions they would be interested in from three categories including: body-focused, mind-body techniques and skill-building interventions. The participants expressed the most interest in programs that included exercise, massage, coping skills training and deep breathing techniques. This study

provides good descriptive data for further nursing interventions that aim to decrease the stress level of family caregivers.

*Worry about the disease.* Patients with a PMBT often experience a very rapid disease trajectory and unpredictable future, which can increase the caregiver's worry. The nature of “worry” contains an existential fear of the unknown. Strang, Strang and Ternstedt (2001) assessed the existential support of caregivers of patients with brain tumors. All of the caregivers were satisfied with the medical and physical treatment offered by providers, but not with the providers' existential support. Many described feeling a “threat” to their family's well-being and wished that they had a supportive venue to discuss their worries and fears.

Edvardsson and Ahlstrom (2007) conducted a qualitative study that explored the experiences of 28 next-of-kin of persons with low-grade gliomas. A major theme that arose in their study was the extremely stressful emotions of the family members. Participants described feeling fear and uncertainty, as many worried that their loved one's tumor might relapse. Many said that they worried every time the patient went to the doctor – hoping that they would not get bad news.

Osse et al. (2006) studied 76 informal caregivers, or non-professional caregivers, of advanced cancer patients and their need for support. The researchers asked participants to fill out a needs assessment questionnaire. They tallied the results into a “Top 20” list of problems. The list included many fears and emotional burdens such as “the fear of an unpredictable future,” “the difficulty of showing emotion” and “difficulty in finding meaning in death.” This study reinforces the need for healthcare professionals

to provide caregivers with support for their fears and worries regarding the patients' illness.

*Worry about finances.* Many caregivers of patients with chronic illnesses experience extreme financial hardship. Covinsky et al. (1994) obtained 2,129 interviews of patients with a serious illness and/or their family caregivers. Over half of the families reported at least one severe caregiving or financial burden. Thirty-one percent of the sample reported losing most of their savings, and 20% reported undertaking a major life change in order to care for the patient, such as quitting a job or taking extended time off from work.

The National Brain Tumor Foundation (2007) published an extensive report on financial fall-out among patients and family members of patients with brain tumors titled "Nobody Can Afford a Brain Tumor." The foundation conducted an online survey of 500 participants including 277 patients with brain tumors and 224 of their caregivers. The report painted a bleak picture of the high cost of treatment even for patients with insurance. In the sample, 59% of patients and 65% of caregivers identified brain-tumor related expenses as a major problem. Both patients and caregivers experienced a decrease in the amount of time they could work. Ninety-one percent of patients worked before diagnosis; however, because of decreased physical and cognitive functioning, only 33% worked after diagnosis. During their family members' illness, 16 % of caregivers had to quit their jobs and 62% had to take a leave absence, take vacation time or cut back on their hours. The survey also found that 48% of those surveyed experienced a decrease in their household income. Most striking, the percentage of people who fell into the



lowest income category, \$0 to \$14,999 annually, increased 300% after diagnosis. This report chronicles the “downward mobility” that occurs after someone is diagnosed with a brain tumor, which can affect the full context of their life. Thus, financial worry is a very common and reasonable worry for caregivers of patients with a PMBT.

*The rewards of caregiving.* The following section explores research, which has found that many caregivers recognize “rewards” during their caregiving experience. This work suggests that despite being complex and challenging, providing care to family members with a terminal illness can be a profound and transformative experience for many caregivers. The rewards of caregiving were not a direct focus of this study; however, a short discussion of them is included in this review in order to provide a balanced perspective of both the positive and negative psychological aspects of caregiving.

Salmon et al. (2005) participated in a three year project, *Caregiving at Life's End*, at The Hospice Institute in Florida. The researchers used a survey to explore the potential rewards of caregiving. They mailed questionnaires to 953 current and bereaved caregivers of hospice or palliative care patients. Their survey asked questions related to self-acceptance, meaning, closure and comfort with caregiving, and tried to determine if these domains were associated with caregiving gain and decreased burden. The findings indicated that higher levels of meaning and comfort in caregiving led to lower burden, while increased self-acceptance and closure led to more caregiver gain. The authors recommend that healthcare providers become more aware of the potential rewards of caregiving and initiate new ways to increase meaning during the caregiving trajectory.

In an intervention study of family caregivers of patients with cancer, Hudson et al. (2005) set out to improve caregivers' levels of preparedness, competence, reward, anxiety, and self-efficacy. To the researchers' surprise, the reward of caregiving was the only significant outcome of the study. The findings showed that it was possible for the nurse to increase the caregiver's optimism toward caregiving - even if the intensity of the caregiving experience was increasing. The study also showed that talking about emotive topics, such as the pending death of the patient, can be helpful for the family caregiver. Block (2001), a palliative care physician, encourages healthcare professionals to help caregivers explore these deeper levels of meaning regarding the illness process and to raise awareness of the potential rewards of caregiving, so that the situation becomes a positive rather than a negative experience.

### *Summary*

Many negative psychological factors including stress, anxiety and worry have been identified as common outcomes of the caregiving experience. These psychological stressors are especially prevalent among family caregivers of persons with a PMBT, due to the patient's rapid disease trajectory and limited treatment options. Although research has shown that many caregivers experience psychological distress, little is known of how this affects the caregiver's performance. More exploratory work on this connection between psychological distress and performance is needed. This information will help nurses develop targeted interventions to assist family caregivers in coping with the psychological distress of caregiving.

### *Situational Factors of the Family Caregiver*

Becoming a caregiver takes place within the context, or situation, of one's life. The situational factor examined in this study was how prepared the caregiver felt to take on the caregiving role. In this study, it was hypothesized that lower levels of preparedness would negatively effect caregiver performance. The concept of "preparedness" was developed by Archbold et al. (1990) in their research with older caregivers. The researchers developed the concept of preparedness together with mutuality. Though mutuality is not examined in this study, it is an integral part of understanding the researchers' conceptual development of "preparedness," and will be discussed in this review.

*Mutuality and preparedness.* Archbold et al. (1990) studied the caregiving experience of older adults. They were interested in the predictive effects of mutuality and preparedness on caregiver role strain. When formulating their definition of mutuality, they drew from the work of Horowitz and Shindelman (1983) who defined mutuality as the affective relationship of caregiving involving past and present closeness, shared activities and the ability to confide in one another. They also cited prior research done by Pruchno and Resch (1989) who found that spousal caregivers who were more emotionally invested in their marital relationship reported lower levels of depression and burden than those who were less emotionally attached. Finally, Hirschfeld (1983) defined mutuality as the ability to find gratification and meaning in the relationship with the impaired person and also meaning in the caregiving situation – even during difficult periods. She concluded that higher levels of mutuality enable caregivers to continue

providing care despite challenging situations. Archbold et al. (1990) later expanded the concept of mutuality by connecting it with preparedness.

To define preparedness, Archbold et al. (1990) explored research done in self-efficacy and caregiving mastery. They built on the work of Haley, Levine, Brown & Bartolucci (1987) who measured the self-efficacy of caregivers and its relationship to depression, life satisfaction and self-rated health problems. They found that higher self-efficacy led to lower levels of depression. Lawton, Kleban, Moss, Rovine and Glicksman (1989) studied caregiving mastery and concluded that it was a vital component of the caregiver appraisal. In their early exploratory work of preparedness, Archbold et al. (1990) once again identified a connection between decreased preparedness and caregiver role strain.

Archbold and her colleagues (1990) realized that, while mutuality and preparedness had been well defined, there was a gap in the literature regarding the systematic examination of the effects of mutuality and preparedness on various aspects of caregiver role strain. To study the predictive value of mutuality and preparedness, they studied 78 family caregivers at six weeks and nine months after hospital discharge. As predicted, they found that lower levels of mutuality and preparedness led to increased caregiver role strain. Their work showed that a positive relationship between the caregiver and the care receiver, and how well-prepared the caregiver felt about caregiving, had a significant positive impact on caregiver role strain.

Schumacher and her colleagues (2007) continued their work exploring the connection between mutuality and preparedness in caregiver outcomes. In their most

recent study they examined whether relationship-quality and preparedness moderated the effects of caregiving demand on caregiver outcomes. The researchers asked 87 family caregivers of patients receiving cancer treatment to fill out a survey detailing their personal characteristics. Using hierarchical multiple regression analyses, caregiving difficulty and overall mood disturbance were regressed in two or three-way interactions with demand, mutuality and preparedness.

Results from the analyses indicated negligible effects in the one and two-way interactions. The most statistically significant outcome occurred in the three-way interaction between demand, mutuality and preparedness. This three-way interaction explained a significant portion of the variance of the caregiver's perceived difficulty in providing care, and their overall mood disturbance. The authors suggest that the three-way interaction is the most interesting outcome of the study. It shows that family caregiving is too complex to be demonstrated in just one or two-way interactions, but is best shown in more complicated three-way interactions. In other words, in order to be a successful caregiver, it is not enough to have a good relationship with the patient; caregivers must also feel well prepared and undertake realistic caregiving demands. One remaining question from Schumacher et al.'s (2007) work, which was explored in the current study, is to what degree caregiver demand and preparedness influence the performance of the family caregiver.

Other researchers in palliative and oncology care have also explored the concept of preparedness. Ferrell et al. (1991) found that family caregivers receive insufficient preparation in responding to symptoms, and often learn to care for their family member

through trial and error. During the overwhelming nature of the caregiving experience, caregivers often realize that they have to learn a whole new body of skills. Hudson et al. (2002) confirm that caregivers felt under-prepared for the impact caregiving would have on them. They identify specific components of the caregiving experience that were difficult to manage including: its unpredictable nature, its excessive autonomy, and the new skill sets that it requires.

Tilden et al. (2004) found that many family caregivers feel under-prepared for the impact caregiving has on them physically and psychologically. In their qualitative study, Hudson, Aranda and McMurray (2002) identified two major deficiencies: preparedness and support. First, family caregivers were often surprised by their degree of autonomy. Many caregivers have no medical or healthcare experience. Even so, they are expected to provide complicated and technical medical care for their family member, such as medication administration. Second, healthcare providers expect caregivers to quickly adapt to the unpredictable nature of caregiving, oftentimes with very little information or support. For example, caregivers may be surprised by their family member's dramatically changing symptoms over time (Hudson et al., 2002)

### *Summary*

Preparedness refers to the individual's feeling of readiness to take on the role of caregiver. The concept, preparedness, is well defined in the family caregiving literature and has been explored in oncology and palliative care research. Even though research has shown that being prepared is important to family caregivers, individuals often feel under-prepared for the challenges of caregiving, and desire more preparation and support

from their health care providers. A remaining question from the current state of the science is how a lack of preparedness can affect the caregiver's performance.

Understanding the relationship between preparedness and performance will provide valuable information to help nurses develop targeted interventions to improve family caregiver preparedness.

### *Physiologic Factors of the Family Caregiver*

This section discusses several physiologic factors pertinent to caregivers of persons with a PMBT including: the caregiver's age, co-morbidities and the level of assistance he or she provides to the family member. Recent research suggests that caregivers, who are very young or very old, have increased health problems or provide high levels of physical care to family members are at an increased risk for role strain. This section will discuss on these physiologic factors, which can influence the caregiver's performance.

*Age.* Research has shown that family caregivers who are either very young or very old have an increased risk for role strain. Though this study did not specifically analyze age as a predictor of caregiver performance, it is discussed here to provide general background information of the caregiving experience. Elders are especially vulnerable because they can get trapped within cycles of loss and may have decreased resources to recover. Loss in the elder years can include loss of a spouse, a friend, siblings, financial stability or health status. Given and Sherwood (2006) identify multiple ways that older caregivers face increased challenges in comparison to their younger counterparts. First, older adults often have more co-morbid conditions, which can

decrease their physical capacity and vitality and make the physical aspects of caregiving more difficult. Second, older caregivers are at higher risk for social isolation.

Compounded loss can inhibit an elder's ability to make social and emotional connections, which can lead to increased feelings of isolation and loneliness (Rokach and Brock, 1997; Killeen, 1998). Without the support of family or friends to help ease the burdens of caregiving, elders may experience higher levels of role strain. Finally, older adults may be less able to advocate for themselves and ask for the help that they need. "Carrying on" in their caregiving role, especially when experiencing high levels of stress, can increase their risk for caregiver role strain.

Three studies found evidence contrary to the supposition that young caregivers are less vulnerable than older ones. Payne et al. (1999) studied informal caregivers of cancer patients receiving palliative care. They found that younger age correlated with higher levels of psychological distress and caregiver role strain. Keir et al. (2006) enrolled 60 caregivers of patients with brain tumors, and asked them to fill out a Perceived Stress Scale with demographic information. They found that younger caregivers of patients with low-grade tumors experienced more stress than older caregivers of patients with higher-grade tumors. In a similar study, Dumont et al. (2006) enrolled 212 family caregivers with advanced cancer and assessed their psychological distress. They also found that younger caregivers experienced more distress than their older counterparts, especially when the death of their family member was imminent. The authors of these three studies suggest that since younger caregivers may be less prepared for the decline and death of a loved one, and they may experience it as a more traumatic



event. Also, younger caregivers often have more social and professional responsibilities, which can make it more difficult for them to keep up with their caregiving tasks in addition to their regular duties.

To date, research shows that caregivers who are either very young or very old are at an increased risk for caregiver role strain. Older caregivers who experience decreased health and social support may be less resilient, and thus more vulnerable to the stress of caregiving. In contrast, younger caregivers may not be emotionally prepared for the decline of a family member and may struggle with the impact of increased responsibilities in conjunction with their busy social and professional lives.

*Co-morbidities.* Caregivers with their own health problems have a higher risk of caregiver role strain than those who are healthy. In one study of caregivers, Navaie-Weliser et al. (2002) conducted telephone interviews with a large national sample of informal caregivers. They found that over one-third of the caregivers reported being in fair-to-poor health or having a serious health condition. Although these caregivers had their own health problems, they provided an average of twenty hours of care per week for their family member. Many of these caregivers reported difficulty providing this care, illustrating how many vulnerable caregivers struggle to provide care to others while suffering from their own health conditions.

Research indicates that intervening with caregivers who are not healthy should be done with care. Jepson, McCorkle, Adler, Nuamah and Lusk (1999) conducted an intervention study that provided homecare aimed to improve the caregivers' psychosocial status. Their study had a surprising reverse main effect, in that caregivers who received

the home care intervention and had physical problems of their own actually scored lower on the psychosocial assessments. The results from this study showed that additional home care interventions may cause even greater burden to some caregivers, especially those who have their own physical problems. The authors hypothesize that this is because nurses may bring the reality of the situation to light and decrease the caregiver's initial feelings of optimism. The authors recommend very careful assessment of homecare caregiver candidates – especially regarding those who have their own health problems.

*Home-based care.* As chronic illness increases, the United States is moving from hospital-based to more home-based care. Experts from the National Family Caregivers Association (2000) estimate that each year more than one-quarter of adults serve as caregivers for ill, disabled or aged family members. Of these caregivers, 37% live in the same household as the patient and 46% provide some type of nursing care such as medication administration or monitoring of vital signs (NFCA, 2000). Kurtz, Kurtz, Given and Given (2004) found that caring for someone in the home, rather than in an institutional setting, demands more intensive care from the family caregiver and can lead to higher levels of depression. The authors believed that caregivers in the home suffer from more strain because they have limited escape from the patient's illness and suffering, and often take on more complex caregiving tasks.

*Degree of assistance provided.* Data from two studies supports the contention that caregivers who provide increased levels of physical care are at a higher risk for caregiver role strain. Emanuel, Fairclough, Slutsman and Emanuel (2000) interviewed

893 caregivers of patients with terminal illnesses in six U.S. cities. They found that patients with poor physical function, incontinence, shortness of breath or depressive symptoms had greater care needs. Subsequently, the caregivers of these patients were significantly more likely than caregivers of patients with low care needs to experience depression and to report that their role as caregiver was interfering with their family or personal life.

In another study, Sherwood et al. (2006) studied the predictors of distress in 95 caregivers of patients with a PMBT. They found that, because a patient with a PMBT often experiences a short illness trajectory and quick physical decline, he or she often requires high levels of assistance from family caregivers. Results from this study show that a patient's increased need of assistance with activities of daily living (ADLs) statistically increases the caregiver's burden – particularly in regard to the caregiver's schedule and health. Both of the studies show that increased physical demands on the family caregiver can lead to increased levels of caregiver role strain.

### *Negative Outcomes of Caregiving*

Researchers have identified numerous negative outcomes which can affect the caregiver's overall health and well-being. This section discusses several of these negative outcomes including: depression (Haley et al., 2001), fatigue (Carter & Chang, 2000), decreased health (Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991), social problems (Kurtz et al., 2004) and, most striking, the higher incidence of mortality (Christakis & Allison, 2006). Although these negative outcomes are not specifically

addressed as variables in this study, they are described in this section in order to give an overall review of the potential risks caregivers face.

*Depression.* Caregiver depression is a mood disturbance that may develop over time as a result of caregiver role strain. Depression presents with multiple dimensions including psychological symptoms, such as anxiety and fear, and physical symptoms, such as decreased appetite and fatigue. Haley et al. (2001) found that caregivers of patients with cancer and dementia both showed higher signs of depression and lower life satisfaction than non-caregivers. They studied 80 spousal caregivers and found that over half of the caregivers presented with clinically significant levels of depression, which was over three times the rate of depression among community dwelling adults.

Kurtz et al. (2004) examined the impact of caregiving on caregivers' mental and physical health over a one year period. They also found that caregivers were more prone to depression than a control group of community dwelling adults. In addition, they found that the caregiver's personal perceptions of the caregiving experience, such as the impact of caregiving on his or her schedule, predicted caregiver outcomes including depression and poor physical health. The authors recommend that healthcare providers recognize the great demands placed on caregivers and periodically assess them for signs of depression or strain.

Two recent studies show a direct correlation between the patient's and the caregiver's level of depression. Fleming et al. (2006) examined the association between perceptions of the quality of healthcare and the quality of life in patients with metastatic cancer vis-à-vis their informal caregivers. They found that the patient's mental health

and depression scores correlated with the mental health and depression of their caregivers, suggesting that mental health is associated with the caregiver/patient relationship. The authors believe that the caregiver and patient evolve as a “unit of care,” which should be assessed equally by the healthcare team. Mystakidou, Tsilika, Parpa, Galanos and Vlahos (2007) echoed these findings in a study of advanced cancer patients and their caregivers. The authors also found that cancer patients' depression correlated with that of their caregivers, and recommend that healthcare providers treat the patient and caregiver as a “patient-caregiver dyad.”

Though interventions to improve depression in caregivers of patients with Alzheimer's disease have been successful, studies in oncology and palliative have shown that intervening with depressed caregivers can be difficult (Mittelman, Roth, Haley & Zarit, 2004). Kozachik et al. (2001) and Kurtz, Kurtz, Given and Given (2005) aimed to decrease depression among family caregivers of cancer patients; however, their interventions did not produce any significant main effect. The interventions contained educational information on symptom management, and included both personal and phone contact with a nurse. The authors hypothesized that the interventions proved ineffective because those participants with the highest levels of depression dropped out of the study more frequently. The authors suggest that more work needs to be done to understand the drop-out rate of depressed family caregivers, so that the attrition rates can be improved.

*Fatigue.* Providing care on a daily basis can cause fatigue and near exhaustion in family caregivers. In one study of 42 caregivers of patients with advanced cancer, Aranda & Hayman-White (2001) found that fatigue was present in about 70% of

caregivers. Most of these caregivers had experienced fatigue over months to years rather than days or weeks. The caregivers noted that the fatigue most impacted their ability to concentrate and to generate enough energy for caregiving tasks.

Caregiving can also affect the quality of sleep. Carter and Chang (2000) recruited 51 caregivers of patients with cancer. Of the sample, 95% of the caregivers reported severe sleep problems including problems with sleep quality, duration, disturbances and daytime dysfunction. During the interviews, the researchers found that many caregivers who had sleep problems were reluctant to use prescription sleep medications because they believed such medications would affect their ability to perform their caregiving duties. These two studies illustrate how caregiving is often a 24-hour job that can negatively impact the caregiver's ability to get enough rest.

*Decreased health.* The persistent distress of caregiving can also have negative effects on caregivers' physical health. Caregivers often rate their subjective health as lower than non-caregivers. Haley et al. (2001) compared 40 older adult spousal caregivers of patients in hospice with cancer and forty older adult spousal caregivers of patients with dementia. The researchers found that caregivers in both groups reported significantly lower subjective health scores than the non-caregiver group. These findings raise concern because self-rated health has been shown to be a valid indicator of objective health and a predictor of increased mortality (Rakowski, Fleishman, Mor & Bryant, 1993).

Caregiving can also affect the body's immune system and ability to heal itself. Kiecolt-Glaser, Dura, Speicher, Trask and Glaser (1991) found that spousal caregivers of

patients with dementia experienced decreased function of their immune system. The researchers studied 69 spousal caregivers who had already been caregiving for an average of five years. These caregivers reported significantly more days of infectious illness, primarily upper respiratory tract infections, than non-caregivers. In another study, Kiecolt-Glaser et al. (1995) found that prolonged psychological distress can also slow wound healing. They studied 13 women caring for a family member with dementia. Participants underwent a 3.5 mm punch biopsy wound, and then healing and the response to hydrogen peroxide was assessed through photography of the wound. The researchers found that wound healing among the caregivers took significantly longer than wound healing in the control group.

*Increased mortality.* Feelings of loss, distress and the physical demands of caregiving can take an extreme toll on caregivers and ultimately lead to increased mortality. Schulz and Beach (1999) followed 103 participants for four years and found that participants who provided care and experienced caregiver role strain had a 63% higher mortality than the non-caregiving cohort. Christakis and Allison (2006) found similar results related to the serious illness of a spouse. In a secondary data analysis of 518,240 hospital records, the researchers found that the first 30 days of a spouse's hospitalization can have negative effects on the health of the caregiver. The findings indicate that a serious illness of a spouse increased the risk of death for the partner to a degree almost as great as if the spouse had died.

*Social isolation.* Feelings of anger and helplessness can put added strain on the caregiver's social network and cause the caregiver to become even more isolated (Tilden

& Weinert, 1987). For many caregivers, a difficult cycle emerges. Faced with the strain and challenge of caring for their family member, caregivers often experience feelings of anger, guilt and helplessness. Overwhelmed with their responsibilities and difficult duties, caregivers may demand more of their family members, co-workers and friends. These individuals may grow frustrated with the caregiver's behavior and withdraw their support. This only contributes further to the caregiver's overall burnout (Stewart & Tilden, 1995; Tilden & Weinert, 1987).

Kurtz et al. (2004) found that this increased social isolation can have a negative impact on the caregiver's health and well-being. The researchers studied 352 caregivers of patients with cancer over one year. They found that if caregiving disrupted the caregiver's schedule, decreased his or her social functioning or created a sense of abandonment by social networks the caregiver was at higher risk for increased depression and decreased health. These studies reinforce the importance of social connectedness for family caregivers.

### *The Performance of the Family Caregiver*

Although caregiving can be arduous and exhausting, most caregivers are task-centered and strive to do everything that they can for their family members. In several research studies, caregivers have identified performance as one of their most important goals (Andershed & Ternstedt, 1999; Persson et al., 1998; Pierce, 1999). They do not limit their care to medical interventions; they also want to be present, hold, talk and provide comfort to their family members. The current study was specifically concerned with the caregivers' performance in the area of symptom management. In this study



performance was measured by the family caregiver's perceived symptom distress of the person with a PMBT. Measuring "perceived symptom distress" is part of a growing body of literature, which has identified a dyadic relationship that occurs between the caregiver and the care receiver, whereby they are influenced by the other's positive and negative outcomes (Fleming et al., 2006; Lobchuk, 2003; Mystakidou et al., 2007; Schulz et al., 2007). The following section discusses the particular challenges of symptom management in the PMBT population and the need for more research and interventions to improve caregiver performance by healthcare providers.

*Caring for the chronically ill.* The median survival of persons with a PMBT varies from one to five years depending on the individual's tumor stage and cellular type (National Cancer Institute, 2007). Many of those patients who live beyond one year face a prolonged and chronic illness, where their caregivers must watch them decline over time. Researchers from the Centers for Disease Control and prevention (CDC) report that chronic diseases, such as heart disease and cancer, are rising (CDC, 2007). Over the last century, seven out of every ten Americans died from a chronic illness. Such prolonged disease trajectories often result in extended suffering and decreased quality of life for millions of Americans and their families.

According to the American Cancer Society (2006) cancer is the second leading cause of death in the United States. In 2003, 556,902 people died from cancer, which includes nearly 23% of all deaths in the United States (ACS, 2006). Cancer was first recognized as a national health problem in 1971 when President Nixon signed the National Cancer Act. Over the last 30 years federal research funding has led to many

advances in cancer diagnosis and treatment (ACS, 2006). As a result, individuals often live longer after a cancer diagnosis than in previous decades, so that, today, cancer is considered more of a chronic illness. Researchers from the National Institutes of Health (NIH) estimate that 60% of cancer patients survive at least five years beyond their initial diagnosis (NIH, 2002). As the longevity of many individuals with cancer increases, many become increasingly frail and dependent on others for assistance. This is especially true of patients with a PMBT, who often suffer progressive decline and disability.

*Symptom management.* The NIH State of the Science Conference on Symptom Management identified symptom management as one of the greatest challenges in cancer care today due to the fact that the identification and palliation of symptoms has not kept pace with treatments (NIH, 2002). Family caregivers of patients with cancer are often significantly involved in symptom management. Aranda and Hayman-White (2001) found that caregivers of patients with advanced cancer encountered an average of 11 symptoms, which require between five to 14 hours of care per week. Emmanuel et al. (2000) surveyed 988 terminally ill Americans living at home and also found a high prevalence of symptoms. In their sample, 71% of patients experienced shortness of breath, 50% suffered moderate to severe pain, 36% had incontinence and 18% experienced fatigue.

Patients with a PMBT are unique because their tumor and treatment cause both oncologic and neurological symptoms. Mukand, Blackinton, Crincoli, Lee and Santos (2001) evaluated the extent of neurological symptoms in persons with primary brain tumors who were admitted to a rehabilitation unit. They found that 75.4% of the patients

had three or more concurrent neurological symptoms and 39.2% had five or more. The most common neurological symptoms included impaired cognition (80%), weakness (78%), visual-perceptual sensory loss (38%) and bowel and bladder dysfunction (37%). This study reinforces the contention that persons with primary brain tumors often suffer from multiple symptoms simultaneously.

Researchers at the NIH have called for more intervention studies to reduce or eliminate the system barriers to adequate symptom management (NIH, 2002). In one descriptive study of palliative care nurses, Johnson, Kassner, Houser & Kutner (2005) found that the most common perceived barriers to effective symptom management include: the inability of family caregivers to implement or maintain the recommended treatments; patients or caregivers not wanting the recommended treatments; and competing demands from other distressing symptoms. This study suggests that symptom management interventions should target not only professional providers, but also the family caregivers, who are continually at the patient's bedside. Since nurses have close relationships with patients and their families, they are in an ideal position to develop targeted interventions.

*Perceived symptom distress and caregiver burden.* In the current study, performance was measured by the caregiver's perceived symptom distress of the person with a PMBT. Measuring "perceived symptom distress" is part of a growing corpus of literature, which has identified a dyadic relationship that occurs between the caregiver and the care receiver, whereby they are each influenced by the other's positive and negative outcomes (Fleming et al., 2006; Lobchuk, 2003; Mystakidou et al., 2007; Schulz

et al., 2007). This research suggests that the caregiver's increased stress can cause increased distress in the patient, and vice versa. Tilden et al. (2004) document a high correlation between the caregiver's perceived symptom distress of the patient and caregiver burden. They studied 1,189 family caregivers of patients who had recently died in community settings. Their findings showed that the following factors were associated with greater caregiver burden: the caregiver's perception of the patient's distress, hospice enrollment, and increased caregiver involvement. The degree of burden was highest among primary caregivers in contrast to those who shared care with others. Their findings suggest that seeing the patient in distress can be one of the most disturbing emotional experiences for the caregiver, and can lead to reciprocal stress and burden for the caregiver.

*Caregivers' need for education and support.* Several qualitative nursing research studies indicate that information and supportive needs are a primary concern for family caregivers (Andershed & Ternstedt, 1999; Hudson et al., 2002; Pierce, 1999; Rose, 1999). Andershed and Ternstedt (1999) note that although caregiving can be arduous and exhausting, most caregivers were task-centered and wanted to do everything that they could for their family members. Pierce (1999) explains that such care does not necessarily refer only to medical interventions, but also to being with their loved ones, holding their hands, talking with them, and keeping them comfortable. Persson et al. (1998) identified caregivers who wanted to help in any way that they could, but felt that the healthcare staff did not use them as a resource. These caregivers described their healthcare workers as absent, misunderstanding their situation, or not asking about their

feelings. These studies uncovered a contradiction that although caregivers want to assist their family member, health care providers do not always recognize them as a resource.

Family caregivers desire more information on caregiving, and these requests should be addressed individually. For example, Rose (1999) found that information needs change over time and should be individualized to each person. She relates how one caregiver was initially convinced that her husband's stomach cancer would recover over time, and held interest only in treatments and "getting better." Three months later she realized that he would not get better, and desired more information about palliative care. Andershed and Ternstedt (1999) found that caregivers wanted to know more about their situation, and learned through multiple resources including the patient, the staff and others. They cite the example of an 86 year-old spouse who did not talk with the medical team, but only discussed the situation with her children. In these various situations, nurses need to be aware of information within the context of each family caregiver.

Hudson et al. (2002) point out that nurses are in a unique position to recognize caregiver role strain. They can provide information and support and also promote caregiver optimism. Nurses can support caregivers by affirming their feelings and frustrations. They can also teach strategies of self-care so that the caregivers do not develop burn-out or a negative view of their role. Providing increased support and education for the caregiver will not only improve the caregiver's skills, but will also help him or her maintain the dignity of the family member (Chochinov, 2002) and explore deeper levels of meaning regarding the dying process (Block, 2001).

### Summary

Healthcare researchers identify caregiving as a risk factor that can lead to many negative outcomes for family caregivers. Healthcare providers expect family caregivers to quickly adapt to the unpredictable nature of caregiving, but often with very little information or support. Although caregiving can be arduous and exhausting, most caregivers are task-centered and strive to do everything that they can for their family members. They do not limit their care to medical interventions, but also want to be present, hold, talk to and comfort their family members.

Performance in symptom management is one of the most difficult tasks for many family caregivers to master. Caregivers often observe negative symptoms in their family members, but are unsure how to treat them. This can lead to increased burden for the caregiver, which can ultimately affect the care recipient. Since nurses work directly with patients and families they are in an ideal position to provide education and support to the caregiver/patient dyad. The first step in this process is to refine the nurse's understanding of the family caregiver's experience of symptom management when caring for a family member with a PMBT. This study explores the effect of caregiver role strain and preparedness on caregiver performance. Information from this study will inform future theory development and nursing interventions, which target family caregivers of persons with a PMBT.

## CHAPTER 3

### Methods

This chapter describes the methodology used in this study including the sample population studied and the recruiting process. This chapter also outlines the data collection procedures and data analysis. The setting for this study was an urban teaching hospital in Boston, Massachusetts.

The study employed a descriptive, correlational research design in which the researcher obtained cross-sectional data during one collection period to test the research hypotheses. The participants of this study were adults, who identified themselves as family caregivers of a person with a PMBT. Data were collected through a self-administered paper and pencil instrument developed to measure the specific variables included in this study.

#### *Study Sample and Setting*

The target population of this study included adults aged twenty-one years or older, who self-identified as the primary family caregiver of person with a PMBT. Specific inclusion criteria included: having a family member 21 years or older diagnosed with primary malignant glial brain tumor; the ability to speak and read English; and the ability to consent to the study.

This study had three exclusion criteria. First, it excluded caregivers who were paid because their dynamic with persons with a PMBT may be different from caregivers who are not paid. Second, it excluded participants who are non-English speakers because the questionnaires have not yet been translated into other languages. In addition, access

to bi-lingual translators for recruitment was limited. And, third, it excluded multiple family caregivers of the same patient because their answers would likely be similar and could have potentially biased the study results. In cases where multiple family members identified themselves as the primary caregiver, the Principal Investigator (PI) asked them to fill out the questionnaire together.

The original planned sample size for this study was 100 participants. This number was based upon a hierarchical regression model with an effect size of 0.20, an alpha of 0.05 and a power of 0.8, as determined by “*Sample Power: Version 2.*” (Borenstein, Rothstein, Cohen, Schonefeld & Berlin, 2002). Since data would be collected at one point in time, there was no expected attrition.

The participants were recruited from the Brain Tumor Center (BTC) at Beth Israel Deaconess Medical Center, a Harvard Medical Center affiliated teaching hospital in urban Boston. The BTC provides a multidisciplinary approach and comprehensive care to patients with primary or metastatic central nervous system tumors. The core staff of the center includes physicians and nurses who have expertise in neuro-oncology, neurosurgery, radiation oncology and neuro-pathology. The PI of this study was employed as a neuro-oncology nurse practitioner at the BTC throughout the duration of the study.

### *Procedures*

Potential family caregivers were contacted by the PI at regularly scheduled visits to the BTC. The PI explained the study's purpose to the potential participants in a private office, and gave them the opportunity to ask questions. Participants were given a letter



containing information about the study with the name and telephone number of the PI (See Appendix B). The PI explained to potential participants that their participation was completely voluntary and would have no effect on their care. They were also informed that they could withdraw their participation from the study at any time.

To protect patient anonymity for both the patient and the caregiver, each participant was assigned a unique identification number, so that their names would not be associated with the data collected. The completed survey was placed in a sealed envelope by the participant. Participants dropped the survey in a collection box at the reception area of the clinic at the end of their appointment. At the end of the day, the surveys were collected, and kept in a locked file to maintain confidentiality.

No potential risks or short term benefits were anticipated for those who chose to participate. Potential participants were advised that the long-term benefit of their participation would be to increase the understanding of family caregivers of persons with a PMBT, which may lead to the development of nursing interventions. If a caregiver was not interested in participating, his or her name was recorded in an excel spreadsheet, so that he or she would not be approached again to participate. This file was kept on a secure private desktop computer.

### *Instruments*

Participants were given a survey to provide their demographic characteristics, levels of caregiver role strain, preparedness and the perceived symptom distress of their family member's physical and psychological symptoms. Participants were asked to fill out the survey in the clinic before or after their appointment. They were not permitted to

complete the survey at home.

*Demographic information.* A demographic questionnaire comprised the first portion of the survey. It was developed by the PI and included questions related to the family caregiver and his or her caregiving experience. Questions related to the family caregiver included: age, gender, race and ethnicity, highest level of education and subjective health. The questions related to their caregiving experience included: the number of care hours provided per day, the duration of providing this amount of care, prior experience as a caregiver, the relationship with the care recipient, the amount of outside or paid help, self-rated social support, the family member's cell type and the duration of the illness (See Appendix C).

*The Family Caregiving Inventory (FCI).* Subscales of FCI were used to measure the situational factor, preparedness for caregiving, and the psychological factor, caregiver role strain, in the subscales of tension, worry and global strain. The FCI, developed by Archbold et al. (1990), measures seven predictor variables, including preparedness, and nine measures of caregiver role strain. Six of the role strain scales from the FCI were not used for two reasons. First, two scales from the FCI had a Cronbach's alpha below .70. Second, four scales in the FCI related to economics and the caregiver/patient relationship. Since these scales were not pertinent to the study questions, they were not included in the instrument battery of this study.

Researchers established content validity of this instrument through a pretest of 50 dyads of family caregivers and care recipients. Results from this pretest were used to refine the final Family Caregiving Inventory. Construct validity was established through

a high correlation between preparedness and caregiver role strain in the areas of strain from direct care, increased tension and global role distress (Archbold, et al., 1990).

Caregiver role strain was measured by respondent scores on three caregiver role strain sub-scales which assessed strain from worry, tension and global strain. In all three scales, respondents answered questions based on a five point scale. For example, “0” indicated “not at all worried,” and “4” indicated “very worried.” One exception is item four in the global strain scale, which was reversed scored so that “0” indicated higher levels of strain, and “4” indicated lower levels of strain (See Appendicies D, E, & G). The final worry subscale included 12 questions. The previous research by Archbold et al. (1990) found that this scale had a Cronbach’s alpha of .82. Possible scores on the worry subscale range from 0 to 46 with higher numbers indicating a higher level of worry. The tension subscale includes four questions with a reported Cronbach’s alpha of .91 (Archbold et. al, 1990). Possible scores from the tension subscale range from 0 to 16 with higher numbers indicating a higher level of tension. The global strain subscale has four questions with a reported Cronbach’s alpha of .78 (Archbold et. al, 1990). Possible scores from the global strain subscale range from 0 to 16 with higher numbers indicating a higher level of global strain. Archbold et al. (1990) reported scores on the caregiver role strain scales by calculating a mean score of all of the items. In this study caregiver role strain was combined by adding the total scores of the three subscales, tension, worry and global strain, and dividing by three.

In this study, preparedness was measured by respondent’s scores on the preparedness sub-scale of the FCI, which included five questions that explore the family

caregiver's perception of his or her own readiness to provide care. Questions include: how well-prepared the caregiver feels to care for the physical and emotional needs of the patient, and how prepared he or she feels to take on the stress of caregiving. Respondents answered the questions on a five point scale with "0" indicating "not at all prepared" and "4" indicating "very well prepared." Possible total scores range from 0 to 20 with higher numbers indicating a high level of preparedness (See Appendix F). This subscale has established reliability with a Cronbach's alpha of .88 to .93 (Carter et al. 1998; Hudson et al., 2005; Silver, Wellman, Galindo-Ciocon & Johnson, 2004). Archbold et al. (1990) cite negative correlations between preparedness and caregiver worry and lack of resources provided as evidence of the instrument's construct validity. They reported scores on the preparedness scales by calculating a mean score of all of the items, which ranged from 0 to 4.

*The Family Memorial Symptom Assessment Scale (MSAS).* The family caregiver's performance was assessed by measuring their perceived symptom distress of their ill family member through a modified version of the MSAS. The complete MSAS instrument is a self-report tool developed for cancer populations to assess symptom frequency, severity and distress (Portenoy, et al., 1994). The instrument contains 32 items, including 26 physical symptoms and six psychological symptoms. The original instrument has a complex scoring system. Severity, frequency and distress are evaluated for 24 of the symptoms on Likert scales with higher scores indicating increased severity, frequency or distress. For example, the instrument presents a symptom such as "dry mouth," and asks the respondent to indicate whether or not it is present. If the symptom

is present, the caregiver is then asked to rate the frequency, severity and distress level of the symptom. Symptom frequency is evaluated on a four point scale with “1” indicating “rare” occurrence to “4” indicating “almost constant” occurrence. Symptom severity is evaluated on a four point scale with “1” indicating “slight” severity to “4” indicating “very” high severity. Symptom distress is evaluated on a five point scale with “0” indicating “not at all” distressing to “4” indicating “very” distressing. For the remaining eight symptoms of the instrument only symptom severity and symptom distress are measured. These include symptoms such as “weight loss” and “I don’t feel like myself” which do not have a relevant “frequency” component. Therefore, for these eight symptoms, only severity and distress are measured.

The original scoring of this instrument includes four separate components. First, the total MSAS score is the mean average of the symptom frequency, severity and distress scores for all 32 items, which provides an overall assessment of global distress. Other scoring methods were developed through a factor analysis of variance, which yielded three subset scoring groups including a psychological (PSYCH), physical (PHYS) and global distress index (GDI). The PSYCH scale includes mean scores for the frequency, severity and distress of six symptoms. The PHYS scale includes the mean scores for the frequency, severity and distress of 12 symptoms. The third scoring component of the MSAS, the Global Distress Index (GDI), is a shorter way to attain an assessment of global symptom distress. The GDI includes the average of the single dimension scores of symptom distress of ten symptoms including the frequency of four psychological symptoms (worry, sad, irritable and nervous) and the distress scores for

seven physical symptoms (lack of appetite, lack of energy, feeling drowsy, constipation, dry mouth, difficulty breathing, and pain).

Validity of the MSAS instrument was established through high correlations with the patient's clinical status and other quality of life measurement tools. Clinically, patients treated in the hospital with more advanced diseases have higher scores than patients treated as out-patients with earlier stage disease. The MSAS also correlated with other established instruments used to measure performance, quality of life and symptom distress, including the Revised Rand Mental Health Survey, Functional Living Index-Cancer, Symptom Distress Scale and Karnofsky Performance Status Scale (Portenoy et al., 1994). Internal reliability has been reported as consistently high with the Cronbach's alpha for the PHYS scale ranging from 0.88 to 0.84, PHYS scale ranging from 0.82 to 0.83 and for the GDI's Cronbach's alpha ranging from 0.82 to 0.84 (Hickman, Tilden & Tolle, 2001; Lobchuk, 2003; Portenoy et al., 1994).

Two modifications were made to the MSAS instrument in this study. These included: limiting the evaluation of one symptom dimension, distress, and the addition of four symptoms pertinent to the brain tumor population, which were not included in the original instrument. The entire MSAS instrument is lengthy and complex. Previous research estimates that it takes approximately 20 minutes to complete, which was thought to be too long when combined with the other instruments used in this study (Lobchuck, 2003). Since this study was primarily concerned with symptom distress, and not symptom frequency or severity, it was decided that the participants should only rate one dimension of the symptom – its distress. This was done to limit the overall length of the

instrument and the potential caregiver burden. Thus, when scoring the instrument in this study, only the ratings of symptom distress on a five point Likert scale from zero to four were averaged to obtain the MSAS total score, perceived psychological symptom distress score and the perceived physical symptom distress score.

Second, four additional symptoms were added, which were not captured in the original MSAS, but were predicted to have a high prevalence in the population of PMBT patients. These included two psychological symptoms (change in mood and agitation) and two physical symptoms (gait and visual changes). Thus, in the final version of the instrument used in this study, the potential range of total scores for the MSAS was 0 to 144, with higher numbers indicating higher levels of symptom distress (See Appendix H). The instrument included eight psychological items with a possible range of 0 to 32, and 28 physical items with a possible range of 0 to 112 and a possible mean score of 0 to 4 for each item. Because of these modifications, the scores of this instrument used in this study differ from previous research, which used the tool in its entirety. However, the mean scores, which measure distress averaged across symptoms, should correlate with previous research.

The MSAS has been used in oncology research. Lobchuk (2003) adapted the instrument for use in oncology research of family caregivers. She evaluated the instrument in a study of ninety-eight family caregivers of patients with advanced cancer. Her results indicated that the majority of caregivers could respond to all of the items; however, questions pertaining to the patient's sexuality were most often left blank. The mean PSYCH score was 1.42 (SD=0.83), the mean PHYS score was 0.96 (SD=0.67), and

the mean MSAS-GDI was 1.46 (SD=0.24). Internal consistency was also high with PHYS ( $\alpha=0.84$ ), PSYCH ( $\alpha=0.82$ ), MSAS-GDI ( $\alpha=0.84$ ). The average item-scale correlation ranged between  $r=0.30$  and  $0.45$ , indicating that the items were moderately to strongly correlated with one another, but were not redundant.

These findings correlate with Hickman et al. (2001) who also evaluated the instrument within a population of palliative caregivers. They calculated a MSAS-GDI to assess eleven physical and psychological symptoms commonly experienced by dying patients. In their study, the mean score of the MSAS-GDI was 1.14 (SD=.87) with a range of 0 to 3.73. The scale demonstrated good internal consistency with a Cronbach's alpha of .82. The average item total correlation was  $r=.49$  and the average inter-item correlation was  $r=.30$ . The scale correlates highly with the RAND well-being scale ( $r=-.66$ ) and RAND distress scale ( $r=.79$ ) suggesting good criterion validity.

*Open-ended questions.* Open ended questions were included at the end of each instrument. These questions were developed by the PI, and allowed the participants to include information that may not have been addressed in the questionnaire. For example, at the end of the survey that measures the degree of worry, an opened ended question asked, "Are there any other things about caregiving, which were not mentioned [in the questionnaire] that you worry about?" These questions gave the participants the opportunity to respond openly to each subject area. This information was used to provide further interpret the data from the instruments.



## Methods

### *Data Collection Process*

Participants were recruited for participation during regularly scheduled appointments at the BTC. Following HIPAA guidelines, the PI reviewed the medical records of patients visiting the clinic prior to their appointment to see if their diagnosis met the study criteria. During the clinic session, the PI introduced herself to the patient when he or she was in a private room. If the patient had someone with him or her, she would ask if that person identifies him or herself as a primary family caregiver. If so, the PI explained the purpose and benefits of the study. If the caregiver was not interested in participating his or her name was recorded in an excel spreadsheet, so that he or she would not be approached again to participate. If more than one family caregiver identified him or herself as the primary caregiver, the PI asked that they collectively fill out the survey together. This occurred in two situations in which two caregivers filled out the survey together.

Participants interested in completing the survey were given the survey packet with an introduction letter (See Appendix B) and six questionnaires (See Appendices C to H). The participants were asked to complete the questionnaires in the clinic, where the PI was available to answer any questions. After completion, the participants were asked to place the questionnaire in a sealed envelope, and then drop them into a collection box that was located in the reception area of the clinic.

### *Protecting Human Participants*

This study involved human participants. The study population of family caregivers included adults over the age of twenty-one. Institutional Review Board (IRB) approval was obtained from BIDMC and Boston College prior to subject enrollment and data collection (See Appendices I & J). The participant's return of the survey served as their consent to participate in the study. The study participants understood that they could withdraw from the study at any time without penalty. Study participants were assured of confidentiality at all phases of the research. The PI explained that their names would not be identified anywhere on the questionnaire, and that all of the data collected would be kept in a locked file and on a secure, private desktop computer. No harmful procedures, situations, or materials that would be hazardous to the participants were anticipated.

### *Proposed Data Analysis*

*Enter the data.* The PI entered all of the demographic and questionnaire data into SPSS Version 15.0. She ran frequencies on all of the variables. If any out-of-range numbers were found, she checked the ID number, reassessed the original data source, and re-entered the correct data if necessary.

*Analyze for missing data.* Next, the PI checked for random or systematic missing data. Random missing data indicates that sporadic values are missing from a few variables. Systematic data indicates that one variable has many missing data points or a high amount of missing data from one or more participants. If systematic missing data was suspected, she would create a new variable with 0=no missing data and 1=missing

data. Then she would run a t-test with this new variable and each dependent variable to determine if systematic missing data existed. If it did, then she would use this new variable as a covariate, or drop the missing cases from the data set. The PI planned to handle missing data in the following three ways: she would drop cases from further analysis; delete variables with missing data; or estimate the data based on a mean substitution.

*Analyze for skewness.* The PI checked for the presence of marked skewness by computing Fisher's coefficient of skewness. This number was calculated by dividing the measure of skewness by the standard error of skewness (Munro, 2005). Values above 1.96 or below -1.96 were considered skewed. If skewness existed, the PI would transform the variable. Next, she would run an analysis with the transformed and the untransformed variables to determine how much influence the skewed variables exert to determine if they should be transformed or not (Norris & Aroian, 2004).

In the final stages of data preparation, the PI checked each variable to ensure that enough data points existed at each level. Most statistical analysis requires a minimum of 90% of recorded data. The PI computed Cronbach alpha internal consistency reliability statistics including all items of each scale to ensure that each scale met the criterion of a Cronbach's alpha greater than .70 (Devellis, 2003). The PI also computed the total scores and the range of scores for all of the study instruments.

### *Testing the Hypotheses*

The hypotheses were tested using regression analyses to determine the extent to which preparedness and caregiver role strain explained the caregiver's perceived

psychological and physical symptom distress. Since some of the instruments had a greater number of items, and might out-weigh other instruments with fewer items, mean total scores of the variables were computed for use in the regression analysis. These included mean total scores for preparedness, caregiver role strain, perceived psychological symptom distress and perceived physical symptom distress. The mean total score was calculated by adding scores of all of the items in a scale and dividing by the total number of items. The mean total score for caregiver role strain was computed by adding the mean total scores from the FCI subscales of tension, worry and global strain and dividing by three. In the regression analyses, mean total caregiver role strain and mean total preparedness were entered as a single block as the independent variables. Mean total psychological symptom distress and mean total physical symptom distress were entered as dependent variables to account for differing numbers of symptoms that could be reported. To control for experiment-wide Type I error in these analyses, the alpha was set at .025 for each of the two hypotheses.

## CHAPTER 4

### Results

This chapter contains six sections that discuss the results from this study. Topics include the treatment of the data, demographic information, internal consistency reliabilities, descriptive data for the dependent and independent variables, total scores of the instruments and a post hoc power analysis. This chapter concludes with the results from the of hypothesis testing of the two regression analyses.

#### *Treatment of Data*

The data were entered into an SPSS version 15.0 data file and then analyzed for outliers, missing data and marked skewness. The Principal investigator (PI) first ran frequencies to check for any data that were outside the appropriate range. When out-of-range data were found, she checked the source and reentered the correct numbers. Second, the PI checked for systematic and/or random missing data. She found no systematic missing data. A small amount of random missing data was found in three surveys. Since the missing data were limited to one or two questions on a subscale, it was decided not to compute a new variable. Instead, when running the regression, she substituted the mean score of each subscale. Third, the PI assessed for the amount skewness of the total scores of the independent variables, preparedness and caregiver role strain, and the dependent variables psychological symptom distress and physical symptom distress. Since none of these variables were skewed, no transformations were necessary.

### *Demographics*

Eligible caregivers were enrolled between February 2007 and November 2007 from the Brain Tumor Clinic at Beth Israel Deaconess Medical Center. Of the 65 caregivers who were identified as potentially eligible for the study, 42 were asked to participate (See Figure 2). Of the 42 caregivers asked to participate, 40 participated and two declined. Beth Israel Deaconess is a teaching hospital which conducts extensive oncology research. The two individuals who declined had already been approached to participate in several other studies. Since they had already enrolled in other clinical trials, they were not interested in participating in additional research.

The PI did not ask 23 eligible caregivers to participate because the clinical situation prompted extreme anxiety, stress and/or sadness. In these cases, the family caregivers were so visibly upset or anxious that support staff such as social workers needed to be called to assist with the clinical appointment. In 16 of these 23 cases, the patients were undergoing their first visit to the Brain Tumor Clinic. This is often a very anxious time, when patients and family members discuss treatment options and meet with multiple providers in neurosurgery and radiation oncology. Because they are meeting with multiple providers and taking in a lot of information, they demonstrated high levels of anxiety during their first visit to the clinic. In the other seven cases, the clinical outcome of the visit prompted a catastrophic reaction. In three cases, the patients transitioned into hospice care during the clinic appointment. This prompted extreme sadness as the terminal nature of the patients' illness became clear. In three cases, the patients' MRIs showed tumor progression. This was an ominous sign for the patients and

family members, since the tumor had returned, and they became very upset. In the last case, a patient was told that she could not drive because of seizure risk. She became very angry and left the clinical visit abruptly. In all 23 of these cases, the family caregiver was deemed too stressed or emotionally upset by the clinical encounter to participate in research.

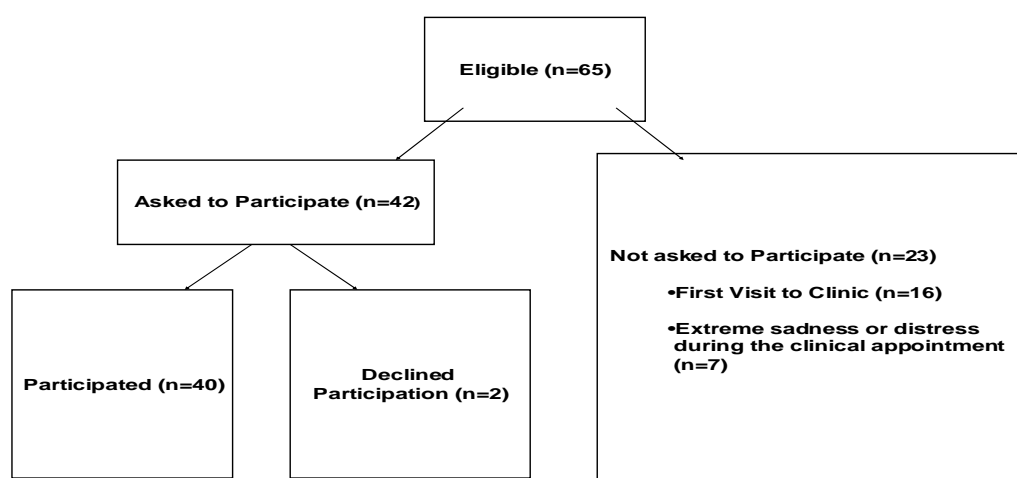


Figure 2. Study Accrual Flowsheet.

The final sample included 40 primary family caregivers of persons with a PMBT. The characteristics of the participants are included in Table 1. The participants had a mean age of 50 years and a range from 26 to 75 years (SD= 10.9). Most were white (87.5%), female (80%), college educated (72.5%), had a spousal relationship with the patient (57.5%) or were a son or daughter of the patient (25%). Most caregivers identified themselves in excellent or good health (87.5%), and reported moderate to high social support from family and friends (75%).

Table 1

*Descriptive Characteristics of Family Caregivers of Persons with a PMBT (n = 40)*

	Range	Mean	Standard Deviation
Age	26-75	49.8	10.9
Length of Illness (months)	0-192	37.1	50.0
		n	%
Gender			
Male		8	20.0
Female		32	80.0
Race			
White		35	87.5
Hispanic		1	2.5
Black		2	5.0
Multi or Bi Racial		2	5.0
Education			
High School		7	17.5
Professional School		4	10.0
College		19	47.5
Graduate School		10	25.0
Relationship			
Spouse		23	57.5
Son or Daughter		10	25.0
Significant Other		4	10.0
Other		3	7.5
Subjective Health			
Excellent		0	25.0
Good		5	62.5
Fair		25	12.5
Poor		10	0.0



The majority of patients had been diagnosed with glioblastoma, (42.5%), oligodendroglioma (35%) or anaplastic astrocytoma (10%). Other pathological cell diagnoses included ganglioglioma, pilocytic astrocytoma and dysembryoplastic neuroepithelial tumor. Seventy-five percent of the sample reported that they were within three years of the patient's initial diagnosis. The length of their illness ranged from 0 to 192 months with a mean of 37 months ( $SD= 50.1$ ).

#### *Internal Consistency Reliabilities*

Internal consistency reliabilities for all instruments and subscales used in the study were computed using Cronbach's alpha. Table 2 displays the alpha coefficient for each instrument or subscale, and the total number of items per scale. All of the instruments had a reliability coefficient greater than 0.70 and were judged satisfactory for use in the study (DeVellis, 2003). Since the internal consistency reliabilities of all study instruments attained an acceptable Cronbach's alpha level of 0.70 or more, total scores for the scales were computed and included in Table 2.

#### *Descriptive Statistics of the Study Instruments*

Table 2 reports all of the descriptive statistics of the instruments including their mean, standard deviation, range of possible scores and actual scores. The total scores of the preparedness subscale from the FCI ranged from 6 to 20 with a mean of 12.90 ( $SD=3.2$ ), indicating a moderate amount of perceived preparedness. The total score of caregiver role strain, computed from the sum of the total scores of the worry, tension and global strain subscales from the FCI, ranged from 10 to 71 with a mean of 35.30 ( $SD=14.2$ ), indicating a higher than average amount of role strain. Since mean total

Table 2

*Instrument Total Scores with Number of Items, Cronbach's alpha, Mean, Standard Deviation, Range of Possible Scores and Actual Scores*

Instrument	Number of Items	Cronbach's Alpha	Mean	SD	Possible Score Range	Minimum Actual Score	Maximum Actual Score
Preparedness Subscale	5	.74	12.90	3.17	0-20	6	20
Caregiver Role Strain Total	20	.90	35.30	14.19	0-80	10	71
Tension Subscale	4	.89	6.53	3.80	0-16	0	16
Worry Subscale	12	.86	23.76	9.37	0- 48	8	47
Global Strain Subscale	4	.74	4.97	3.55	0- 16	0	15
MSAS Total	36	.89	27.92	16.9	0-144	1	68
MSAS Global Distress Index	11	.78	11.98	7.06	0-44	1	30
Physical Symptoms Distress	28	.86	16.78	12.49	0-112	0	48
Psych. Symptom Distress	8	.85	11.15	7.07	0- 32	1	31

scores were used in the regression analysis and for comparison to previous research these scores are reported in Table 3.

The total score of the Memorial Symptom Assessment Scale (MSAS) ranged from 1 to 68 with a mean of 27.92 (SD=16.9), indicating a moderate level of distress. The physical symptom distress score from the MSAS ranged from 0 to 48 with a mean of 16.78 (SD=12.5) indicating a moderate level of distress with possible scores ranging from 0 to 112. The psychological symptom score ranged from 1 to 31 with a mean score of 11.15 (SD=7.1) indicating a moderate level of distress with possible scores ranging from 0 to 32. Since mean total scores were used in the regression analysis these scores were reported in Table 3.

The MSAS-GDI subscale was also computed to compare totals with previous work, and will be discussed further in Chapter 5. It should be noted, however, that since this MSAS tool was modified in this study, an exact comparison can not be made to previous research. However, since the GDI scale was only slightly modified in the current study, it is the best scale to use as a comparison. To recap, the GDI includes the average of the single dimension scores of symptom distress of ten symptoms including the frequency of four psychological symptoms (worry, sad, irritable and nervous) and the distress scores for seven physical symptoms (lack of appetite, lack of energy, feeling drowsy, constipation, dry mouth, difficulty breathing, and pain). The one change made to the scale in this study was that symptom frequency was not measured for the four

Table 3

*Instrument Mean Scores with Mean, Minimum, Maximum and Standard Deviation*

	Mean	Min.	Max.	Standard Deviation
Caregiver Role Strain*	1.62	.39	3.31	.70
Tension	1.63	0	4.00	.95
Worry	1.98	.67	3.92	.78
Global Strain	1.24	0	3.75	.86
Preparedness	2.58	1.20	4.00	.63
MSAS Global Distress Index	1.24	0	3.75	.86
Psychological Symptom Distress	1.39	.13	3.88	.88
Physical Symptom Distress	0.60	0	1.71	.45

\* Mean Caregiver Role Strain = Mean Tension + Mean Worry+ Mean Global Strain/ 3

psychological symptoms -- instead symptom distress was measured. All other components of this scale were computed in the same way as in previous studies. In this study, the MSAS-GDI scores ranged from 1 to 30 with a mean of 11.98 (SD=7.1) indicating a moderate level of symptom distress with possible scores ranging from 0 to 44.

The prevalence of specific symptoms on the MSAS is detailed in Table 4. The five most prevalent symptoms included the psychological symptoms (worry, lack of concentration and sadness) and two physical symptoms (lack of energy and drowsiness). Caregivers reported from 1 to 28 symptoms with a mean of 13.58 (SD = 6.7) symptoms.

#### *Open Ended Questions*

Qualitative data was obtained via open-ended questions at the end of each section of the survey instrument. This data was compiled and analyzed for recurrent themes. In regard to tension, family caregivers felt the most tense when trying to balance their family member's illness with their finances, childcare duties and caring for aging parents. In regard to worry, family caregivers explained that they worried the most about when and how their family members' illness would get worse. In regard to preparation, participants identified the need for more preparation for the patients' anticipated change in condition, and in the subsequent increase in the feelings of anxiety and emotion that this would prompt. Finally, in the open-ended questions following the MSAS, participants identified memory and speech symptoms, as significant problems that were not part of the instrument.

Table 4

*Family Caregiver Responses Regarding Presence or Absence of Symptoms (n = 40)*

Item	% Report of Symptom Prevalence
Worry*	92.5
Difficulty Concentrating*	72.5
Sadness*	70
Lack of Energy	70
Drowsy	70
Irritable*	62.5
Nervous*	60
Agitated*	60
Problems with Gait	57.5
Changing Moods*	57.5
Difficulty Sleeping*	55
Hair Loss	45
Constipation	42.5
Pain	42.5
Dizzy	37.5
Problems with Sexual Interest or Activity	37.5
Changes in Skin	37.5
Change in Taste	35
Visual Problems	35
"I don't look like myself"	35
Bloated	32.5
Lack of Appetite	30
Nausea	30
Weight Loss	30
Itching	27.5
Swelling of arms/legs	27.5
Dry Mouth	25
Shortness of Breath	22.5
Vomiting	17.5
Numbness or Tingling in Extremities	17.5
Cough	10
Difficulty Breathing	10
Problems with Urination	7.5
Mouth Sores	7.5
Difficulty Swallowing	5
Sweats	2.5

\* Psychological symptoms

### *Post Hoc Power Analysis*

In order to verify the adequacy of power to detect relationships hypothesized in this study, a post-hoc power analysis using “*Sample Power: Version 2.*” (Borenstein et al., 2002) was conducted. The power analysis was based on the regression model with two predictors, caregiver role strain and preparedness, and one dependent variable, perceived symptom distress. Results for hypothesis one, calculated with the dependent variable, perceived psychological symptom distress, indicated that with a sample size of 40 and alpha set at 0.05 the study had a power of 0.81. Results for hypothesis two, calculated with the dependent variable physical symptom distress, indicated that with a sample size of 40 and alpha set at 0.05 the study has a power of 0.96. Thus, it was determined that a sample of 40 family caregivers supplied enough power to perform the two regression analyses for the hypothesis testing.

### *Findings Related to Research Questions*

*Preparing the data.* Since some of the instruments had a greater number of items, and might out-weigh other instruments with fewer items, mean total scores of the variables were computed for use in the regression analysis. These included mean total scores for preparedness, caregiver role strain, perceived psychological symptom distress and perceived physical symptom distress. The mean total score was calculated by adding all of the items in a scale and dividing by the total number of items. The mean total score for caregiver role strain was computed by adding the mean total scores from the FCI subscales of tension, worry and global strain and dividing by three.

*Multicollinearity.* Prior to the regression analysis, collinearity between the independent variables of role strain and preparedness was assessed using criteria recommended by Tabachnick and Fidell (1996). Collinearity is determined by two factors including a conditioning index greater than 30 and at least two variable proportions greater than 0.50. Since the data did not meet these criteria, multicollinearity was not identified as an issue in this regression analysis.

*Research hypothesis one.* Family caregivers who rate themselves with higher levels of caregiver role strain and lower levels of preparedness will have increased levels of perceived psychological symptom distress when caring for persons with a PMBT.

In hypothesis one, regression analysis procedures were applied to examine how much of the variance in perceived psychological symptom distress was explained by the variables, caregiver role strain and preparedness. A standard regression analysis, in which all of the independent variables are entered at once, was performed (Munro, 2005). The mean total scores of caregiver role strain and preparedness were entered together as the independent variables. The mean total score of psychological symptoms distress was entered as the dependent variable.

Caregiver role strain and preparedness explained 35% of the variance of perceived psychological symptom distress ( $F=9.87$ ,  $df\ 2, 37$ ,  $p=.000$ ). When adjusted for shrinkage error as suggested by Munro (2005) the explained variance was reduced to 31% (adjusted  $R^2$ ). Caregiver role strain was the major contributor ( $B=.68$ ,  $p=.000$ ), indicating that higher levels of caregiver role strain were predictive of higher levels of perceived symptom distress and this relationship was strong. Preparedness contributed



less to the explained variance ( $B=-.24$ ,  $p=.20$ ). The negative beta indicates that higher preparedness was related to lower perceived symptom distress, but this relationship was small and the change in  $R^2$  was non-significant when role strain was already in the equation (See Table 5).

*Research hypothesis two.* Family caregivers who rate themselves with higher levels of caregiver role strain and lower levels of preparedness will have increased levels of perceived physical symptom distress when caring for persons with a PMBT.

In hypothesis two, standard regression analysis procedures were applied to examine how much of the variance in perceived physical symptom distress were described by the variables of caregiver role strain and preparedness. The mean total scores of care giver role strain and preparedness were entered as the independent variables, and the mean total score of physical symptom distress was entered as the dependent variable of the analysis.

Results in Table 4 indicate that caregiver role strain and preparedness explained 33% of the variance of perceived physical symptom distress ( $F=9.04$ ,  $df\ 2, 37$ ,  $p=.001$ ). When adjusted for shrinkage error the percent of explained variance was reduced to 29% (adjusted  $R^2$ ). Caregiver role strain explained more of the variance ( $B=.48$ ,  $p=0.001$ ), indicating that higher levels of caregiver role strain were predictive of higher levels of perceived physical symptom distress and this relationship was strong. Preparedness contributed less to the explained variance ( $B= -.21$ ,  $p=.14$ ). The negative beta means that higher preparedness was related to lower physical perceived symptom distress, but this

relationship was small and the change in  $R^2$  was non-significant when role strain was already in the equation.

*Univariate analysis.* Following the regression analysis, the relationship between the independent (caregiver role strain and preparedness) and dependent variables (perceived psychological and physical symptom distress) was further analyzed through univariate correlation analysis. Preparedness was significantly related only to perceived physical symptom distress ( $r = -.32, p = .04$ ), indicating that higher levels of caregiver preparedness were associated with lower perceived physical symptom distress in the care recipient. While the relationships of preparedness to caregiver role strain ( $r = -.27, p = .11$ ) and perceived psychological symptom distress ( $r = -.30, p = .06$ ) were both in the expected direction, and were of moderate strength, they did not achieve statistical significance in the univariate analysis. Caregiver role strain was positively related to both perceived psychological symptom distress ( $r = .54, p = .001$ ) and to perceived physical symptom distress ( $r = .51, p = .001$ ), indicating that the greater the role strain, the greater the perceived symptom distress, both physical and psychological, in the care recipient. The relationship between the two types of perceived symptom distress was also significant ( $r = -.45, p = .004$ ). Overall, the results of the univariate analysis further supported the

Table 5

*Summary of Standard Regression Analyses for the Prediction of Perceived Symptom Distress of Persons with a PMBT*

Independent Variable	Psychological Symptom Distress			Physical Symptom Distress		
	Beta	Standard Error	P Value	Beta	Standard Error	P Value
Caregiver Role Strain	.68	.19	.00	.48	.10	.00
Preparedness	-.24	.18	.20	-.21	.09	.14
R	.59			.57		
R Square	.35			.33		
Adjusted R Square	.31			.29		
R Square Change	.35			.33		
F Change	9.87			9.03		
Significant F Change	.00			.00		

Inclusion retention of all variables in the theoretical model.

### Summary of the Findings

Results from the regression analyses indicated that caregiver role strain and preparedness explained 31% of the variance (adjusted  $R^2$ ) in perceived psychological symptom distress and 29% (adjusted  $R^2$ ) of the variance in perceived physical symptom distress. Caregiver role strain was the major contributor to psychological symptoms ( $B=.68$ ,  $p=.000$ ) and physical symptoms ( $B=.48$ ,  $p=0.001$ ), indicating that higher levels of caregiver role strain were predictive of higher levels of perceived symptom distress and this relationship was strong. Preparedness contributed less to the explained variance in psychological symptoms ( $B=-.24$ ,  $p=.20$ ) and physical symptoms ( $B=-.21$ ,  $p=.14$ ). The negative beta indicates that higher preparedness was related to lower perceived symptom distress, but this relationship was small in comparison to role strain. In summary, caregiver role strain and preparedness explained a significant amount to the variance in the caregivers' perceived symptom distress; however, caregiver role strain was a stronger predictor.

## Chapter 5

### Discussion

The purpose of this study was to identify the extent to which preparedness and caregiver role strain explained the family caregiver's performance in symptom management, as conceptualized by the perceived symptom distress of his or her family member. This chapter discusses the study findings in four sections. The first section provides a discussion of the demographic and instrument characteristics. Section two presents an interpretation of the study results of each hypothesis. In section three the limitations of the study are discussed. The last section explains how this study impacts future research, practice, policy and theory and makes recommendations for each of those areas.

#### *Caregiver Characteristics*

*Family caregiver demographics.* The sample in this study was recruited from the Beth Israel Deaconess Medical Center Brain Tumor Clinic from February 2007 to November 2007. Participants had relatively homogenous demographic characteristics. As shown in Table 1, the mean age of participants was 50 years old, although there was also a wide age range. They were mostly white (87.5%), female (80%) and college educated (72.5%). Most had a spousal relationship with the patient (57.5%) or were a son or daughter of the patient (25%). The study sample lacked ethnic, racial and cultural diversity; however, the sample was representative of the population seen at this clinic.

Of note, the vast majority of participants in this study rated their subjective health as either excellent or good (87.5%), and none reported their health as poor. This is

contrary to the work of Haley et al. (2001) who compared caregivers of patients in hospice and caregivers of patients with dementia with a non-caregiver group, and found that the caregivers reported significantly lower subjective health scores than the non-caregivers. Since this study was done in a cross-sectional format, it is not known whether the subjective health rating of the caregivers would decline during the caregiving experience. A future longitudinal study is needed to show how the subjective health of caregivers changes over the duration of the caregiving experience.

Although the caregivers in this study reported low subjective health, 75% of the sample rated support from family and friends at a moderate or high level. It is interesting to note that despite these high levels of support, caregivers in this study still reported moderately high levels of caregiver role strain. These findings suggest that even caregivers who have strong social support experience increased caregiver role strain, and thus, are in need of additional nursing interventions to improve their caregiving experience.

*Cell type.* As reported in Chapter Four, patient characteristics include cell diagnosis of the following: glioblastoma (42.5%), oligodendroglioma (35%) or anaplastic astrocytoma (10%). These numbers are consistent with the Central Brain Tumor Registry of the United States (CBTRUS). In its most recent epidemiological report in 2006, CBTRUS found that the occurrence of glioblastoma was statistically more common than both oligodendroglioma and anaplastic astrocytoma (CBTRUS, 2006).

*Duration of the illness.* Seventy-five percent of the sample was enrolled in the study within three years of the patient's initial diagnosis. There was a wide range in the

patients' length of illness from 0 to 192 months with a mean of 37 months. This illness duration is consistent with the National Cancer Institute's estimate, which found that most patients with primary brain tumors can expect rapid debilitation and a median survival time of one to five years (National Cancer Institute, 2007). It is also consistent with Sherwood et al.'s (2006) study of caregivers of patients with a PMBT. In their study, the patients' length of illness ranged from 2 to 216 months ( $M=33$ ) with 75% of the patients diagnosed within three years. This demographic information, combined with the reported levels of perceived symptom distress perceived by caregivers in this study, provide evidence that patients with lower grade gliomas may live longer, but often suffer from considerable physical and psychological symptoms (See Table 4). An interesting question raised by these findings is how the patients' symptoms and disease progression interact with the caregivers' experience over the trajectory of the illness.

#### *Instrument Characteristics*

This section describes the characteristics of each instrument used in the study. First, the instruments from the Family Caregiving Inventory, used to measure caregiver role strain, including the tension, worry and global strain sub-scales, are discussed (Steward & Archbold, 1986). Next, the findings related to the preparedness scale are discussed and compared to previous literature. The final section discusses the results of the MSAS scale, used to measure the caregiver's perceived symptom distress of the person with a PMBT, and compares the results from this study to previous oncology and palliative care research (Portenoy et al., 1994).

*Tension.* The participants' level of tension was measured by the tension subscale from the Family Caregiving Inventory. Participants had a mean score of 1.63 (SD=.95) with a range from 0 to 4 which indicated the presence of moderate tension. This level of tension is consistent with other research, which has shown that family caregivers' stress/tension levels are much higher than those of a community control group (Dumont et al., 2006; Keir et al., 2006; Payne et al., 1999).

The tension scores of this sample were slightly lower than those in Archbold et al.'s (1990) study which reported a mean score of 2.09 (SD=1.0) and a range from 1.00 to 4.00. Archbold et al.'s higher score may have occurred because caregivers in their study were providing care to care-receivers, who were age 65 or older and needed assistance with activities of daily living (ADLs). Research has shown that caregivers who provide increased levels of physical care are at a higher risk for higher levels of stress and tension (Emanuel et al., 2000; Sherwood, 2006). In comparison, care recipients in this study included young adults and individuals who did not need any assistance with their ADLs. Qualitative data obtained from the participants in this study indicated that the caregivers felt the most tension when trying to balance their family members' illness with their finances, child care duties and their responsibility to care for aging parents.

*Worry.* Participants' level of worry was assessed by the worry subscale from the Family Caregiving Inventory. The participants reported a worry mean score of 1.98 (SD=.78) with a range of 0.67 to 3.92, which indicated a moderate to high level of worry. Scores from this subscale were the highest of the three caregiver role strain scales used in this study. This high to moderate level of worry is consistent with other research, which



has shown that caregivers of patients with brain tumors often experience increased levels of worry (Edvardsson & Ahlstrom, 2007; Osse et al., 2006; Strang et al., 2001). Scores from this study were slightly lower than Archbold et al.'s (1990) study which reported a mean score of 2.43 (SD=.77) and a range from 1.11 to 3.89. Qualitative data obtained from this scale showed that the most common cause of worry for caregivers is the probability that their family members' illness will get worse.

*Global strain.* Participants' global strain was assessed by the global strain subscale from the Family Caregiving Inventory. The global strain scores were the lowest of the three caregiver role strain subscales. Participants reported a global strain mean score of 1.24 (SD=.86) indicating small to moderate levels of global strain with a range from 0 to 3.75. These scores were significantly lower than Archbold et al.'s (1990) study which reported a mean score of 2.30 (SD=.84) and range from 1.00 to 4.00. Again, Archbold et al.'s (1990) higher score may be because caregivers in their study were providing care to care-receivers, who were age 65 or older and needed assistance with ADLs.

*Preparedness.* Participants recorded how prepared they felt to take on the caregiving role on the preparedness subscale of the Family Caregiving Inventory. Participants reported a preparedness mean score of 2.58 (SD=.63) and a range from 1.20 to 4.00. These scores indicate that participants from this study felt moderately prepared to care for their family member. Results from this study correlated with Hudson et al. (2005) who conducted a psycho-educational intervention for 106 family caregivers of patients receiving palliative care. The researchers obtained a baseline measurement of

the caregivers' preparedness with a mean score of 2.66 (SD=0.92). Results from this study also correlate with both Archbold et al.'s (1990) study, which reported a mean score of 3.00 (SD=.52), suggesting a moderate level of preparedness, and Schumacher et al.'s (2003) study, which reported a mean preparedness score of 2.76 (SD=0.58).

*Caregivers' perceived symptom distress of the patient.* The perceived symptom distress of participants was assessed through the MSAS. The Memorial Symptom Assessment Scale Global Distress Index (MSAS-GDI) was calculated to compare results from this study to previous research. The mean of the MSAS-GDI in this study was 1.09 (SD= .64) with a range from .09 to 2.73. This is similar to results from Lobchuck's (2003) study of caregivers of patients with cancer. They reported a MSAS-GDI mean score of 1.46 (SD=0.24). This study also correlates with Hickman et al. (2001), who assessed caregivers of patients at the end-of-life and reported a MSAS-GDI mean score of 1.14 (SD=0.87).

The most common symptoms reported in this study were primarily psychological and included worry (92.5%), difficulty concentrating (72.5%), sadness (70%), lack of energy (70%), and feeling drowsy (70%). These symptoms correlated with Lobchuck's (2003) most common symptoms including a lack of energy (89.8%), worry (82.5%), sadness (75.3%), and feeling drowsy (72.4%). The one symptom from this study that did not appear in Lobchuck's general oncology patients was the difficulty with concentration. This finding makes clinical sense since general oncology patients do not experience as many neuro-cognitive symptoms as brain tumor patients.

Hickman et al. (2001) used the MSAS-GDI subscale in their study, and thus only assessed the prevalence of the ten symptoms in that subscale. The most common symptoms found in their study included lack of energy (67%), difficulty breathing (65%), dry mouth (60.2%), feeling drowsy (59.2%) and pain (59.2%). Two symptoms (lack of energy and feeling drowsy) correlated with this study. The other three symptoms (difficulty breathing, dry mouth and pain) are more consistent with patients at the end-of-life, and thus did not correlate as well with the results from this study.

Qualitative data obtained from this section of the study instrument showed that memory and speech problems were the most commonly observed symptoms that were not included in the MSAS instrument. This is consistent with clinical practice, since the prevalence of neuro-cognitive problems is more pervasive in the brain tumor population (Lovely, 2004). Mukand et al. (2001) studied patients with brain tumors in a rehabilitation setting and found that that 75.4% of the patients had three or more concurrent neurological symptoms and 39.2% had five or more. Future studies of family caregivers of patients with a PMBT should include measurement tools that capture more of these neuro-cognitive symptoms.

### *Interpretation of the Findings*

The purpose of this study was to identify the extent to which preparedness and caregiver role strain explained the family caregiver's performance in symptom management, as conceptualized by the perceived symptom distress of their family member. Results from the regression analyses indicated that caregiver role strain and preparedness explained a significant amount of the variance in perceived psychological

and physical symptom distress; however, caregiver role strain was the major contributor, while preparedness contributed less. The following section will discuss how the implication of these findings on future research and practice within this population of caregivers.

*Findings related to the TOUS.* The results from this study support the adapted theoretical framework of the TOUS, whereby psychological and situational influencing factors (unpleasant symptoms) affect performance. The clinical observations of family caregivers of persons with a PBMT led to an important modification of the TOUS in this study. In the original TOUS, influencing factors cause unpleasant symptoms, which lead to decreased performance. In the modified version of the TOUS, the influencing factors can not be separated from their unpleasant symptoms. In other words, the situational and psychological factors of caregiver role strain and preparedness do not cause unpleasant symptoms, but instead they are the unpleasant symptoms themselves. Results from the regression analyses indicate that the psychological factor (unpleasant symptom), caregiver role strain, had the strongest effect on caregiver performance, while the situational factor (unpleasant symptom), preparedness, had less effect. These findings support the use of the adapted TOUS within this population, as an effective model to examine the affect of different variables on the caregiver's performance.

*Findings related to caregiver role strain.* The results of this study support the use of Archbold et al.'s (1990) concept of caregiver role strain in the population of caregivers of persons with a PMBT. In this study, participants' scores on the three subscales, tension, worry and global strain, provided evidence that caregiver role strain was present

in moderate amounts. Subsequent regression analyses further indicated that caregiver role strain had a statistically significant effect on their performance, as measured by perceived symptom distress. Thus, the results from this study reinforce the applicability of the concept of “caregiver role strain,” and its potential effect on the performance of family caregivers of persons with a PMBT.

This study expands Archbold’s et al.’s (1990) concept of caregiver role strain by linking it with performance. Archbold et al.’s (1990) and Schumacher’s (2007) work originally examined the effect of mutuality and preparedness on caregiver role strain and other caregiver outcomes; however, they did not explore the effect of caregiver role strain on performance. This study makes a connection between caregiver role strain and performance, namely that higher levels of caregiver role strain can lead to decreased performance.

*Findings related to preparedness.* Preparedness was not a significant contributing factor to caregiver performance in the context of the theoretical framework of this study. When entered together, role strain and preparedness explained a significant portion of variance of perceived psychological and physical symptom distress; however, in both regression analyses caregiver role strain outweighed preparedness, so that preparedness did not make a significant additional contribution to the dependent variable, perceived symptom distress. These findings suggest that Archbold et al.’s (1990) theoretical concept of preparedness may not be directly applicable to the performance of family caregivers of persons with a PMBT for several possible reasons.

First, the concept of preparedness is domain specific, and refers to the individual's ability to take on the role of caregiver. Data from this study suggests that family caregivers of persons with a PMBT may have felt prepared to take on the role of caregiver – but struggled more with the tension, strain and worry that resulted from their caregiving experience. These results suggest that caregivers of patients with a PMBT struggle more with caregiver role strain than with preparedness. Problems with caregiver role strain are likely due to the ill family member's limited prognosis, rapid decline and little hope for curative treatment. A question that remains from this study is how the caregiver's level of preparedness fluctuates over the trajectory of the family member's illness.

Second, Archbold et al.'s (1990) preparedness subscale addresses the caregiver's ability to care for physical and emotional aspects of the family member, but it does not address the psychological or neuro-cognitive aspects. When univariate analysis was conducted to determine if preparedness had a significant relationship with any of the other study variables, the only variable to have a significant relationship with preparedness was perceived physical symptoms distress (Pearson's correlation  $-.320$ ,  $p=0.044$ ). In other words, caregivers who felt more prepared perceived less physical symptom distress in their family member. It is interesting to note that those caregivers who felt more prepared did not perceive less psychological symptom distress. Archbold and Stewart's (1986) instrument does not capture questions regarding the preparedness for the psychological or neuro-cognitive symptoms, which are very common in persons

with a PMBT. Therefore, items may need to be added to this scale to make it more applicable to caregivers within this oncology population.

Third, the interaction between caregiver role strain and preparedness may be more complicated than what a simple regression analysis can show. In their most recent work on family caregiving, Schumacher et al. (2007) examined whether relationship-quality and preparedness moderated the effects of caregiving demand on caregiver outcomes. Using hierarchical multiple regression analyses, caregiving difficulty and overall mood disturbance were regressed in two or three-way interactions with demand, mutuality and preparedness. Results from the analyses indicated negligible effects in the one and two-way interactions. The most statistically significant outcome occurred in the three-way interaction between demand, mutuality and preparedness. The authors suggest that the three-way interaction is the most interesting outcome of the study because it shows that family caregiving is too complex to be demonstrated in just one or two-way interactions, but is best shown in more complicated three-way interactions. The authors recommend performing these kinds of multivariate caregiver profiles, because they support the development of targeted interventions to assist caregivers in areas where they need the most help. In the current study, the relationship of preparedness with caregiver role strain may be too complicated to fully understand from a one-way regression analysis. Further studies may need to conduct two or three-way analyses to determine the full effect of preparedness.

Fourth, in this study, caregiver role strain overpowered preparedness in the regression analysis. Individual caregiver profiles would be needed to determine the

individual levels of preparedness and caregiver role strain for each caregiver. Previous work has noted that caregiving is complex, and requires tailored interventions to meet the needs of the individual caregiver (Archbold Stewart & Miller, 2004; Schumacher et al. 2006). Future studies could determine the caregiver's profile, including their level of caregiver role strain and preparedness, and then develop tailored interventions to address their individual profile as it changes over time. For example, a caregiver with high role strain and high preparedness might benefit most from an intervention focused on coping; a caregiver with high role strain and low preparedness might benefit most from a coping and symptom management intervention; while a caregiver with low role strain and low preparedness might benefit most from a symptom management intervention.

#### *Limitations and Recommendations*

This study was the first step in obtaining a snapshot in time of how preparedness and caregiver role strain affect family caregivers' performance. This study was limited by a small sample size, limited generalizability, and a cross sectional methodology. Future studies could be improved by adding additional study sites and using a longitudinal methodology.

The final sample size in this study was smaller than anticipated, due to challenges with recruitment. Although *post hoc* power analysis revealed sufficient power for hypothesis testing, the sample was too small to conduct sub-group analyses. The moderate-to-strong effect of role strain in the two analyses ( $B = .68$ ,  $B = .48$ ) and low-to-moderate effect of preparedness ( $B = -.24$ ,  $B = -.21$ ) were stronger than anticipated, based on previous research. This increased the power and also supported their inclusion in



future studies of family caregivers of persons with a PMBT. However, the interaction of these variables with perceived health and perceived social support need to be explored in a larger study. Furthermore, evaluation of potential differences in perceptions of preparedness and role strain based on age, relationship or timing in the illness trajectory would require a larger sample.

Chapter Four included a flow chart that detailed how 23 participants, who met the inclusion criteria, were not included in the study due to their perceived vulnerability. This population of caregivers presented a recruitment dilemma. The challenge was maintaining a balance between objectivity, asking every eligible person to participate, with subjectivity, not asking a person who was extremely stressed or emotional. Since family caregivers of patients with a PMBT can be vulnerable, future studies examining this population may require more than one study site to achieve an adequate sample size. Sherwood et al. (2006) recruited from five sources including national support organizations, a statewide cancer registry, and two urban brain tumor treatment centers. In addition, it should also be noted that in this study, the PI was a practicing NP at the Brain Tumor Clinic. In order to prevent any future bias, the PI may want to consider using a nurse not directly employed at the clinic to recruit participants.

A second limitation in this study was the lack of diversity in the sample that limits generalizability. Because the sample was relatively homogenous it can not be determined if gender, race, or educational status had any effect on the outcome. Future studies with more than one research site may help to increase participant diversity. A third limitation of this study was its cross sectional methodology, which did not show

change over time. This study took the first step in neuro-oncology nursing research to identify how caregiver role strain and preparedness affect performance; however, it only captured caregivers at one time point. Future longitudinal studies would be needed to show how the variables, caregiver role strain, preparedness and perceived symptom distress, fluctuate over the duration of the family member's illness.

#### *Recommendations for Future Research*

The findings from this study support that caregiver role strain and preparedness are two separate factors that can influence caregiver performance. Determining individual caregiver profiles of role strain and preparedness could enable nurses to provide tailored interventions to improve caregiver performance. In this study, caregiver role strain had significantly more impact on caregiver performance, and provided further data that caregivers are at risk for psychological burden. Schulz et al. (2007) make a connection between the caregiver's psychological burden and suffering. They discuss how suffering can present in three different forms including physical, emotional and existential suffering. The findings from this study suggest that emotional and existential suffering are common in caregivers of patients with a PMBT. Schulz et al. (2007) argue that caregiving research has ignored the concept of suffering, because it is not fully understood. They recommend that further research should address the caregiver's experience of suffering in order to determine the most appropriate ways to intervene.

Existential and emotional suffering emerged from the caregivers' reports of moderate levels of strain, worry and tension. Schulz et al. (2007) thoroughly reviewed suffering in their work and provide a compelling picture of the potential burden

caregivers face; however, further refinement of suffering within the population of family caregivers of persons with a PMBT is needed. Strang et al. (2001) conducted a preliminary study that assessed the existential support of caregivers of patients with brain tumors. All of the caregivers interviewed were satisfied with the medical and physical treatment offered by providers, but not with the providers' existential or emotional support. Many described feeling a “threat” to their family's well-being and wished that they had a venue to discuss their worries and fears.

I would be interested in developing a subsequent qualitative study to explore the existential and emotional suffering of family caregivers of persons with a PMBT, and how healthcare providers could improve care and support in this area. Existential research would best be explored by an existential methodology. Phenomenology approaches a question without preconceived theory or bias and allows the truth to unfold through the teller. Previous phenomenological research has been done to explore the experience of caregivers of persons with Alzheimer’s disease, and has uncovered several themes including: “being immersed in caregiving,” “enduring stress and frustration” and “suffering through the losses” (Butcher, Hollkup & Buckwalter, 2001). In a future qualitative study, I would be interested in posing the question: “We have found that many caregivers of patients with a PMBT have difficulty coping with the tension and worry that occur as a result of their family members’ illness. Did you have trouble coping, and, if so, what could healthcare providers have done to help?”

Further exploratory work could lead to the development of a coping intervention to help manage the tension and worry associated with this caregiving population. In

previous work, Swartz and Keir (2007) found that stressed caregivers are willing to participate in interventions to reduce tension. The participants expressed the most interest in programs that included exercise, massage, coping skills training, and deep breathing techniques. My background in pastoral care and Buddhist meditation may provide a good framework for a coping intervention. A concern, however, would be whether caregivers would be willing to add another “task” to their already busy lives. Previous research has shown that intervening with already stressed caregivers can sometimes have a negative impact on their performance (Jepson et al., 1999). Information from a qualitative study could provide the best data on how caregivers would prefer that healthcare providers intervene.

### *Implications for Nursing*

*Practice.* Data from this study provides evidence that caregiver role strain is prevalent in this population of caregivers, especially in the forms of strain, tension and worry. Existential suffering can be addressed through supportive clinical services including professional counseling and pastoral care. In my own clinical practice I have observed that a counselor, who is outside the direct care circle, can serve as a positive, objective therapeutic resource; however, these professionals are usually not called upon until the patient and/or caregiver has reached a crisis point. Since caregiver role strain is so high in the population, counseling services should be offered at the onset of diagnosis, as a standard of care for every patient and family caregiver.

Though nurses and nurse practitioners are not professional counselors, they can be trained to offer supportive listening and guidance during their clinical encounters with

patients and caregivers. The findings from this study support three clinical recommendations for nurses. First, nurses should be aware that caregivers are at a high risk for role strain despite their level of social support. Often when a patient presents to clinic with multiple family members and friends, services are not initiated because social support seems high, and the clinician surmises that the caregiver's needs are low. However, this study suggests that even a caregiver who seems to have strong social ties is at risk for role strain, and should be assessed and offered supportive services.

Second, findings from this study indicate that worry is high in caregivers of patients with a PMBT – especially in regard to the patient's illness trajectory. Because the potential for worry is so high, healthcare providers should address the caregiver's worries in the clinical encounter by simply asking, "Is there anything that you are worrying about?" This discussion would help to uncover the caregiver's worries and determine if they are clinically supported. In my practice, I have observed that caregivers sometimes worry about things that are not clinically substantiated. For example, one caregiver seemed especially quiet and withdrawn during a clinical encounter. When I asked what was bothering her, she said that she noticed a bright spot on the last MRI, and thought that her family member's tumor was growing. In fact, this bright spot was a mechanical artifact, and did not present any evidence of tumor progression. This clinical example shows that even though nurses can not change the course of a patient's illness, he or she can explore the caregiver's worries and help to balance them with the true clinical picture of what they should expect.

Third, since tension and strain are high in caregivers of patients with a PMBT, nurses should discuss stress management as part of the regular clinical visit. Caregivers strive to do the best they can for their family member, and sometimes need permission to take a break in order to care for themselves. Nurses can encourage a stressed caregiver to participate in exercise, a support group or a night of respite. Providing this “prescription” for stress-relieving activities would give the caregiver permission to take a break, and prevent increased levels of caregiver role strain.

During clinical visits clinicians should also help caregivers strive to find meaning within the caregiving experience. Previous work has shown that caregiving can be a transformative experience. Salmon et al. (2005) found that caregivers with higher levels of meaning and comfort in caregiving experienced lower burden, and caregivers with feelings of increased self-acceptance and closure experienced more caregiver gain. In an intervention study conducted with family caregivers of patients with cancer, Hudson et al. (2005) set out to improve caregivers' levels of preparedness, competence, reward, anxiety, and self-efficacy. To the researchers' surprise, the reward of caregiving was the only significant outcome of the study. Their findings showed that it was possible for the nurse to increase the caregiver's optimism toward caregiving - even if the intensity of the caregiving experience was increasing. In both studies, the authors recommend that healthcare providers become more aware of the potential rewards of caregiving and initiate new ways to increase meaning during the caregiving experience. This could be done in the clinical setting by simply asking caregivers if they have found meaning in their experiences and helping them to discuss their feelings.

*Research.* During this study I realized that vulnerable populations pose special challenges to a nurse researcher, who strives to be both objective and ethical. In other words, he or she must provide each person with the opportunity to participate, but not place undue burden on individuals who are already under immense stress. Maintaining this balance between objectivity (as researcher) and subjectivity (as care provider) is more difficult in palliative care and oncology research where patients' illnesses are often a matter of life and death.

In this study, recruiting caregivers in the clinical setting provided both benefits and burdens. A benefit was the ability to screen caregivers, explain the study and have them participate within one time period -- so that zero participants were "lost" to follow-up. A burden of this setting was that several patients and their caregivers received "bad news" during the clinical encounter, which was extremely upsetting. When a patient had a change in condition that prompted a catastrophic reaction, his or her caregiver was not asked to participate in the research study.

Sherwood et al. (2006) performed similar research with caregivers of persons with a PMBT, but took a different approach to recruitment. They advertised their study and asked interested caregivers to contact the primary investigator. The benefit of this methodology was that the participants were self-referred and not experiencing extreme stress or emotion that can occur during a clinic appointment. The burden was that the self-referral process took considerable time and effort. Their final sample included 95 participants, who were recruited from five different sources including two national brain tumor support organizations, a statewide cancer registry and two brain tumor treatment

centers. Future researchers will need to weigh the benefits and burdens of these recruitment strategies when developing their own research design.

In future studies, I would make one specific change to the inclusion/exclusion criteria to exclude caregivers of patients who were coming to the clinic for the first time. During the development of the study it was hypothesized that filling out the survey instrument in the clinic would not add significant burden to family caregivers; however, during the course of the study, it became evident that this was dependent on the nature of the patient's visit. During their first trip to the clinic, caregivers were often overwhelmed by the complexity of the treatment that their family members faced, and were too anxious to participate in research from a clinician's perspective.

Though they are stressed and vulnerable, this study supports the feasibility of further research with caregivers of patients with a PMBT. Williams (2007) addresses recruitment challenges in end-of-life research and identifies the phenomenon of "gatekeeping." This is a process whereby health care providers try to protect patients and their caregivers by preventing them from participating in research. Participants in this study were vulnerable because their loved ones were diagnosed with a terminal illness; however, many caregivers expressed gratitude that someone "cared about them" and was trying to improve the caregiving experience. They also expressed the desire to help others through their participation, so that things could "get better." In this study, caregivers of patients with a PMBT were overwhelmingly willing to participate in research, which should dissuade "gatekeeping" within this vulnerable population. To



prevent any bias in future research, the PI may also want to consider having a nurse, who is not directly employed at the clinic perform recruitment.

*Theory development.* In this study I chose to look at the world through the particular lens of an adapted theoretical framework of the TOUS infused with the work of Archbold et al., (1990). This model proved relevant to family caregivers of patients with a PMBT, and can contribute to further knowledge development in caregiver performance. I believe that the most significant contribution of this model on family caregiver research is its ability to present different influencing factors (or symptoms) that may affect the caregiver's performance. In this study, I chose to examine caregiver role strain and preparedness, but future studies could examine other physiologic, psychological or situational factors including subjective health or social support. Refining the complex factors that influence performance could lead to a richer understanding of the caregiving experience and more tailored nursing interventions

An important modification of the TOUS was made in this study by combining the concepts of influencing factors and unpleasant symptoms, in order to reflect the clinically observed experience of family caregivers. In the original TOUS, the physical, psychological and situational factors cause unpleasant symptoms, which ultimately lead to decreased performance. For family caregivers of persons with a PMBT, influencing factors could not be separated from their unpleasant symptoms. Thus, in this study the psychological factors (worry, tension and global strain) and the situational factor (preparedness) simultaneously became both the influencing factors and the unpleasant symptoms of the caregiver that affected their performance. This is an important change

in the TOUS for caregivers of patients with a PMBT since the psychological and situational factors that influence their caregiving experience can not be separated from their suffering.

Even though preparedness did not contribute a significant amount of variance in the regression models of this study, it should not be eliminated from the theoretical framework. Although it did not reach significant levels, preparedness did contribute a small amount of variance to the regression models, and its negative beta weight indicated that decreased preparedness led to decreased performance, as hypothesized. In addition, univariate analysis found that preparedness had a significant relationship with the perceived physical symptom distress of the patient. It would be interesting in future studies to add a question to the preparedness instrument, asking caregivers if they felt prepared for the psychological and neuro-cognitive aspects of caregiving. Adding this question might increase the relationship of preparedness with the perceived psychological symptom distress of the patient. Another interesting question raised by this study is how the levels of preparedness change over time. A future study could assess whether preparedness has more effect on performance earlier in the patient diagnosis, when levels of caregiver role strain are likely lower. More research is needed longitudinally to explore these sensitive changes of the caregiver's preparedness over time.

In this study the operational definition of performance, defined as the caregiver's perceived symptom distress of the patient, proved effective, but needs further refinement. Caregivers strive to do their job well, and feel that performance is important (Pierce, 1999; Person et al., 1998). In this study, it was assumed that the caregiver's performance

was related to his or her perception of the patient's distress. In other words, a caregiver who was having greater difficulty managing symptoms was expected to rate the perceived symptom distress of their family member higher. This study obtained a snapshot in time of the caregiver's performance, but further work is needed longitudinally in order to determine the relationship of caregiver role strain and perceived symptom distress over the duration of the patient's illness.

It is possible that the caregiver's own distress influenced the perception of their family member's distress (McPherson, Wilson, Lobchuck & Brajtman, 2008). Research has shown that the patients and caregivers operate as a dyad, whereby they are influenced by each other's positive and negative outcomes (Mystakidou et al, 2007; Fleming et al., 2006). This concept of "perspective-taking," or the caregiver's accurate perception of their family member's illness experience, is being explored in oncology research (Lobchuck, 2006). In this study the caregiver's perceived symptom distress of the patient was an indicator of his or her performance in symptom management, and, thus, only determined if the caregiver (and not the patient) was in need of further interventions. Further work on "perspective-taking" needs to be done to determine if the caregiver's subjective ratings should initiate patient-focused interventions.

*Policy.* Neuro-oncology research has traditionally focused on treatment related research; however, the last decade has shown a growing interest in quality of life studies. Although there is great hope for the innovative treatments of tomorrow, there is a growing realization that healthcare providers must also focus on the quality of life of those patients and caregivers living with brain tumors today. Nurse researchers should

continue to promote the importance of quality of life research and lobby for balanced research dollars.

### Conclusion

The purpose of this study was to identify the extent to which preparedness and caregiver role strain explained the family caregivers' performance in symptom management, as defined by their perceived symptom distress of the person with a PMBT. Results from the regression analyses indicated that caregiver role strain and preparedness explained a significant amount of variance in the perceived distress of the patients' physical and psychological symptoms. Caregiver role strain was the major contributor, while preparedness contributed less to the explained variance. This study informs clinicians in neuro-oncology that caregiver role strain is often high in family caregivers of patients with a PMBT and can have a negative impact on caregiver performance. These findings also support the need for more tailored nursing interventions to assist caregivers with ways to decrease caregiver role strain and improve caregiver preparedness.

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## Appendix A

WHO Classification of Glial Tumors of Neuroepithelial Tissue (Adapted from Kleihues & Cavenee, 2000).

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### **Astrocytoma Tumors**

Diffuse Astrocytoma  
Anaplastic Astrocytoma  
Glioblastoma  
Pilocytic Astrocytoma  
Giant Cell Astrocytoma

### **Oligodendroglial Tumors**

Oligodendroglioma  
Anaplastic oligodendroglioma

### **Mixed Gliomas**

Oligoastrocytoma  
Anaplastic oligoastrocytoma

### **Ependymal Tumors**

Ependymoma  
Anaplastic ependymoma  
Myxopapillary ependymoma  
Subependymoma

### **Chloroid Plexus Tumors**

### **Glial Tumors of Uncertain Origin**

Astroblastoma  
Gliomatosis cerebri  
Choroid glioma of the third ventricle

### **Neuronal and Mixed Neuroal-Glial Tumors**

Gangliocytoma  
Dysembryoplastic neuroepitheal tumor  
Ganglioglioma  
Central neurocytoma  
Paraganglioma of the filum terminale

## Appendix B

## Letter to Potential Participants

[BOSTON COLLEGE LETTERHEAD]

Nadine M. Linendoll, PhD(c), MDiv, APRN  
15 North Beacon St. Apt #607  
Allston, MA 02134

February 12, 2007

Dear Potential Study Participant,

You are being invited to take part in a research study titled, *Family Caregivers' Perceived Symptom Distress of Persons with a Primary Malignant Brain Tumor*. This study is exploring aspects of caregiving including how prepared you feel, and how distressing symptoms are for your family member. You are being invited to participate in this research study because you are helping to take care of a family member with a primary brain tumor. If you take part in this study, you will be one of about 100 people to do so.

Your participation is completely voluntary. Your decision whether or not to participate will have no effect on your relationship with your family member's care providers or affect the care you that your family member receives in any way. Please ask questions if there is anything that you do not understand. You may discontinue your participation at any time.

The person doing this study is Nadine Linendoll, a doctoral student at Boston College. She is being guided by Professor Ellen Mahoney in the School of Nursing at Boston College. No funding has been received for this study, and neither Miss Linendoll nor Professor Mahoney expects to receive any extra money from companies because of this research study.

If you would like to participate, please fill out the attached survey. It asks questions about your experience as a caregiver. Please complete the survey in the clinic, and then drop it in a collection box in the reception area. There will be no cost for you to participate in this study, and your name and the name of your family member will not be identified with any information that you share. The survey should take about 10 to 15 minutes to complete.

To the best of my knowledge, filling out this survey will cause you no additional harm to you than what you would experience in everyday life. If you take part in this study, you will help advance the knowledge of family caregiving, which may contribute to future nursing interventions aimed to help family caregivers, especially of persons with brain tumors.

You are encouraged to ask questions now, and at anytime during the study. If you have further questions, you can reach Nadine Linendoll at 814-504-4122 or Professor Mahoney at 617-552-4262. If you have any questions about your rights as a participant in a research study, please contact Boston College Office for Human Research Participant Protection at (617) 552-4778 or Beth Israel Deaconess Medical Center Office for Human Research Participant Protection at (617) 667-1827. Thank you very much. I am looking forward to hearing from you.

**Sincerely,**

**Nadine M. Linendoll, PhD(c), MDiv, APRN**  
**Doctoral Student**

**Ellen Mahoney, DNSc, RN**  
**Assoc. Professor of Nursing**



## Appendix C

## Demographics Questionnaire

Please answer all of the following questions and do not leave ANY question blank. If you need help, please ask Nadine for assistance.

Please answer the following questions about **YOU**. Please **circle** the **number** that corresponds to your answer, or write your answer in the blank where appropriate.

1. What is your <i>age</i> ?	
2. What is your <i>gender</i> ?  1 Male 2 Female	
3. What is your <i>race</i> or <i>ethnicity</i> ?  1 White 2 Hispanic 4 Asian 5 Multi or Bi Racial Other	
4. What is your highest level of <i>education</i> ?  1 High School 2 Professional School 3 College 4 Graduate School	
5. How do you rate your health now as compared to other adults your age?  1 Excellent 2 Good 3 Fair 4 Poor	
6. What is your <i>relationship</i> with the care recipient?  1 Husband 2 Wife	

3 Brother 4 Sister 5 Son 6 Daughter Other:	
7. How many hours of care do you provide each day to your family member?	
8. How long have you been providing this care?	
9. Did you have any prior experience as a caregiver?	
10. How much support do you have from other family members or friends?  1 A great deal 2 Some 3 A little 4 None	
11. How much help have you received from outside agencies (like home health aides or housekeeping services)?  1 A great deal 2 Some 3 A little 4 None	
12. What is your family members diagnosed cell type?	
13. When was your family member diagnosed?	

## Appendix D

## Family Caregiver Inventory: Role Strain Scale Worry

As a caregiver, how much do **YOU** worry about the following? Please **circle** the **number**, which corresponds to the amount that you worry.

How much do you worry about...	Not at all	A little	Some	Quite a bit	A great deal
1. Your family member's health condition?	0	1	2	3	4
2. Obtaining enough help for the things you can't do for him or her?	0	1	2	3	4
3. His or her mood or state of mind?	0	1	2	3	4
4. Financial problems related to his or her care?	0	1	2	3	4
5. Your ability to continue taking care of him or her because of your own health?	0	1	2	3	4
6. How you can go on if he or she gets worse?	0	1	2	3	4
7. Having to leave him or her alone when you go out? (If you never leave, if you had to go out, how much would you worry?)	0	1	2	3	4
8. Your own future?	0	1	2	3	4
9. Who will take care of him or her if something happens to you?	0	1	2	3	4
10. Whether the care and advice you receive from doctors and nurses are adequate?	0	1	2	3	4
11. The negative effects of taking care of him or her on the rest of your family?	0	1	2	3	4
12. The progression of his or her disease?	0	1	2	3	4

**13. Are there any other things about caregiving, which were not mentioned above that you worry about?**

## Appendix E

## Family Caregiver Inventory: Role Strain Scale Tension

As a caregiver, do **YOU** feel tension regarding any of the following? Please **circle** the **number**, which corresponds to the amount of tension that you feel.

Has assisting your family member...	Not at all	A little	Some	Quite a bit	A great deal
1. Increased the stress in your relationship with him or her?	0	1	2	3	4
2. Added tension to your life?	0	1	2	3	4
3. Increased the nervousness and depression you have concerning your relationship with him or her?	0	1	2	3	4
4. Increased your anxiety about things?	0	1	2	3	4

**5. As a caregiver, do you feel tension about anything else that was not mentioned above?**

## Appendix F

## Family Caregiver Inventory: Caregiver Role Strain Scale Preparedness

Some people may feel well prepared for some aspects of caregiving, and not as well prepared in other aspects. How **WELL PREPARED** do you think **YOU** are to do each of the following, even if you do not do that type of care now? Please **circle** the **number**, that corresponds to how prepared you feel.

How prepared do you feel ...	Not at all	Not too well	Somewh at well	Pretty well	Very well
1. To take care of your family member's physical needs?	0	1	2	3	4
2. To take care of your family member's emotional needs?	0	1	2	3	4
3. To find out about and set up services?	0	1	2	3	4
4. For the stress of caregiving?	0	1	2	3	4
5. Overall, how well prepared do you think that you are to care for your family member?	0	1	2	3	4

**6. As a caregiver, is there anything else that you would like to be better prepared for that was not mentioned above?**

## Appendix G

## Family Caregiver Inventory: Role Strain Subscale Global Strain

Please answer the following questions related to **YOUR** overall caregiving experience.  
Please **circle** the **number**, which corresponds to the amount you feel.

	None	A Little	Somewhat	A Lot	Very Much
1. How confined do you feel because of all of the caregiving things that you do for your family member?	0	1	2	3	4
2. How often would you say that taking care of your family member is very difficult?	0	1	2	3	4
3. How much stress do you feel because <b>all</b> of your obligations, including taking care of your family member?	0	1	2	3	4
4. How much do you agree with the following statement, "The positive aspects of caregiving outweigh the negative aspects?"	0	1	2	3	4

## Appendix H

## Family Memorial Symptom Assessment Scale

**This questionnaire asks questions about the physical and psychological symptoms of your FAMILY MEMBER**

**Please indicate whether or not your family member has each symptom by circling YES or a NO. If your family member HAS the symptom, then please rate HOW DISTRESSING it is from 0 “Not at all” to 4 “Very Much.”**

Does your family member...	Yes/No	Not at all	A little bit	Somewhat	Quite a bit	Very Much
1. Feel sad?	Y/ N	0	1	2	3	4
2. Worry?	Y/ N	0	1	2	3	4
3. Feel irritable?	Y/ N	0	1	2	3	4
4. Feel nervous?	Y/ N	0	1	2	3	4
5. Difficulty concentrating?	Y/ N	0	1	2	3	4
6. Difficulty sleeping?	Y/ N	0	1	2	3	4
7. Changing moods?	Y/ N	0	1	2	3	4
8. Feel agitated?	Y/ N	0	1	2	3	4
9. A lack of appetite?	Y/ N	0	1	2	3	4
10. A lack of energy?	Y/ N	0	1	2	3	4
11. Feel drowsy?	Y/ N	0	1	2	3	4
12. Constipation?	Y/ N	0	1	2	3	4
13. Dry mouth?	Y/ N	0	1	2	3	4
14. Pain?	Y/ N	0	1	2	3	4



15. Nausea?	Y/ N	0	1	2	3	4
16. Vomiting?	Y/ N	0	1	2	3	4
17. Change in taste?	Y/ N	0	1	2	3	4
18. Weight loss?	Y/ N	0	1	2	3	4
19. Feeling bloated?	Y/ N	0	1	2	3	4
20. Dizziness?	Y/ N	0	1	2	3	4
21. Gait or balance?						
22. Problems with sexual interest or activity?	Y/ N	0	1	2	3	4
23. Itching?	Y/ N	0	1	2	3	4
24. Cough?	Y/ N	0	1	2	3	4
25. Problems with urination?	Y/ N	0	1	2	3	4
26. Shortness of breath?	Y/ N	0	1	2	3	4
27. Sweats?	Y/ N	0	1	2	3	4
28. Difficulty swallowing?	Y/ N	0	1	2	3	4
29. Mouth Sores	Y/ N	0	1	2	3	4
30. Numbness or tingling in hands or feet?	Y/ N	0	1	2	3	4
31. Visual changes	Y/ N	0	1	2	3	4
32. Difficulty breathing?	Y/ N	0	1	2	3	4
33. Hair loss?	Y/ N	0	1	2	3	4

34. Swelling of the arms and legs?	Y/ N	0	1	2	3	4
35. "I don't look like myself?"	Y/ N	0	1	2	3	4
36. Changes in skin?	Y/ N	0	1	2	3	4

**33. Can you list the three symptoms that you found to be the most distressing for your family member?**

**34. Does your family member experience any other symptoms that were not listed above?**

## Appendix I

## Boston College IRB

**BOSTON COLLEGE****Institutional Review Board**

Office for Human Research Participant Protection

Carney 116

Phone: (617) 552-4778, fax: (617) 552-0948

**IRB Protocol Number: 07.007.01**

DATE: February 9, 2007

TO: Nadine Linendoll

CC: Ellen Mahoney, Ph.D.

FROM: Institutional Review Board – Office for Human Research Participant Protection

RE: Family Caregivers' Perceived Symptom Distress Of Persons With A Primary Malignant

Brain Tumor

**Notice of IRB Review and Approval****Expedited Review as per Title 45 CFR Part 46.110, FR 60366, FR, # 6 and 7**


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The project identified above has been reviewed by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
2. You will immediately inform the Office for Human Research Participant Protection (OHRPP) of any injuries or adverse research events involving subjects;
3. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
4. The protocol qualified for a waiver of informed consent under 45 CFR 46.116 (d);
5. You will give each research subject a copy of the informed consent document;
6. **If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 60 days prior to the IRB approval expiration date. Without continuing approval the Protocol will automatically expire on February 9, 2008.**

## Appendix J

## BIDMC IRB

**From:** Guo,Jack (Bidmc)  
**Sent:** Wed 1/10/2007 10:57 AM  
**To:** Linendoll,Nadine (BIDMC - Nursing)  
**Subject:** Notification of Activation 2007-P-000006

**II.** Notification of Activation

**Protocol #: 2007-P-000006/2 ; BIDMC**

**To:** Nadine Linendoll, PhD(c), MDiv, APRN  
**Title:** Family Caregivers' Perceived Symptom Distress of Persons with a Primary Malignant Brain Tumor  
**IRB Approval Date:** 01/10/2007  
**Expiration Date:** 01/09/2008

**All committee requirements for the research application referenced above have been met. This research application is activated for recruitment and enrollment of subjects. This certifies that the research application was reviewed by the Committee on Clinical Investigations (CCI), the appropriately Institutional Review Board (IRB) and Privacy Board appointed to review all research involving human subjects at a convened CCI meeting. The IRB voted to approve this research application. In their review, the IRB specifically considered the rights and welfare of the individual(s) involved; the appropriateness of methods used to secure informed consent; and the risks and potential medical benefits of the investigation.**

**This expedited study is approved for one year under category 7 unless otherwise stated.**

**The purpose of the study is to obtain a better understanding of the family caregivers' experience of symptom management when caring for persons with Primary Malignant Brain Tumor (PMBT). Specifically, this study will identify the extent to which preparedness and caregiver role strain explain the family caregivers' perceived symptom distress of person with PMBT. Data collected in this study will inform future nursing interventions aimed to improve family caregiver' symptom management skills. The overall goal of this study is to improve the nursing care of persons and their families with PMBT.**

**Note: The following has been reviewed and approved:  
 Full Board Research Application (Part A, B, C, M, O, Q – Eric Wong; Suriya Jeyapalan)**

### HIPPA Waiver of Authorization

The CCI /Privacy Board has determined that the Request for Waiver of Authorization satisfies the criteria for waiver. This waiver of authorization is approved for the use and/or disclosure of Protected Health Information (PHI) for the referenced protocol in the manner described below.

Recruitment: Conversations with prospective research subjects

The following persons or class of persons at BIDMC will have access to (use) of PHI: Members of the BIDMC research team as mentioned in the protocol

The PHI to be used or disclosed includes: Names

### **INVESTIGATOR, please note the following:**

- 1. Use only IRB approved copies of the consent form(s), questionnaire(s), letter(s), advertisement(s), etc. in your research. Do not use expired consent forms.**
- 2. Any modifications or changes made to the study must be submitted to the IRB in writing for review. The IRB must approve all changes before they can be initiated.**
- 3. Any serious and/or unexpected adverse event in a study subject and/or death of a subject is to be reported to the IRB within 24 hours followed by a written report within 10 working days of the event. Any moderate or mild adverse event in a study subject is to be reported to the IRB within 14 working days of the event.**
- 4. The BIDMC assurance number is: FWA00003245 Form FDA 1572 and NIH grant submissions or follow-up certifications for this protocol should reference the appropriate institutional assurance number.**
- 5. This research study expires a year from the Full Board Meeting, and will require continuing review prior to that date. It is the responsibility of the investigator to complete the necessary requirements to secure this approval.**

Please contact the Committee on Clinical Investigations (CCI) at E/FN 201, or call (617) 667-0476, with any questions you may have. Information can also be found on the CCI website: <http://research.bidmc.harvard.edu/OST/ClinicalTrials/default.asp>.

Alan Lisbon, M.D.  
Chairman, Committee on Clinical Investigations

January 10, 2007  
Date of Correspondence

Appendix K  
Permission for FCI Instrument

**From:** Patricia Archbold [mailto:Archbold@ohsu.edu]  
**Sent:** Sat 2/10/2007 12:03 PM  
**To:** Linendoll, Nadine (BIDMC - Nursing); Patricia Archbold  
**Cc:** barbaraj.stewart@gmail.com  
**Subject:** Re: Family Caregiving Inventory

Hello Nadine,

You have our permission to use the scales that you identified. I have copied Dr. Barbara Stewart on this response. As you move forward, if you have any questions about the scales, please contact her. Barbara is a psychometrician and is most familiar with the scales, their validity and reliability, and other psychometric properties.

Pat

Patricia G. Archbold, DNSc, RN, FAAN  
 Professor Emerita  
 OHSU  
 Program Director  
 Building Academic Geriatric Nursing Excellence  
 American Academy of Nursing

>>> <nlindendo@bidmc.harvard.edu> 02/09/07 5:47 AM >>>  
 Hello Pat,

I was in touch with you last year about using the Family Caregiving Inventory in my dissertation study. I am a PhD candidate at Boston College in the dissertation phase. My advisor is Ellen Mahoney. The title of my study is "Family Caregivers' Perceived Symptom Distress of Persons with Primary Malignant Brain Tumor." I plan to use the preparedness and role strain scales (tension, worry, and global strain) in my study, and would like to submit for formal permission. I have IRB approval -- and plan to start collecting data soon.

Could you please recommend the best way for me to request formal permission?

Thank you,  
 Nadine

Nadine M. Linendoll, PhD(c), MDiv, APRN  
 Nurse Practitioner, Beth Israel Deaconess Medical Center